The Psychosocial Impact of Lung Cancer and its Treatment on the Patient and their Primary Carer

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" Come in under the shadow of this red rock,
And I will show you something different from either
Your shadow at morning striding behind you
Or your shadow at evening rising to meet you:
I will show you fear in a handful of dust."

(From the Waste Land:
The burial of the Dead,
T.S.Eliot, 1922)

Abstract

This study has described the psychosocial impact of lung cancer and its treatment of patients and their "primary carers". The subjects have been identified and assessed at three different stages of the illness using a battery of scales and questionnaires. The first group of patients were interviewed at the mid point of their first line chemotherapy regimen. The second group have completed a full course of chemotherapy and have been on follow up observation for at least one month. The third group of patients have received a full course of chemotherapy, a period of follow up observation and were interviewed at the mid point of palliative radiotherapy. There were 40 patients in each group and their "primary carers". (In this study the "primary carer" has been defined as the person who undertakes to provide the majority of the physical and emotional care of the patient.)

There was no statistically significant difference in mean anxiety and depression scores (HAD scale) between the three groups of patients, but a significant number of patients in each group scored in the "case level" range. Similarly, there were no statistically significant differences in mean anxiety and depression scores (HAD scale) between the three groups of "primary carers". The mean anxiety scores of carers were significantly higher than the patients' scores in each of the three groups and a significantly greater number scored in the "case level" range. The psychological state of the patient and the carer are significantly correlated during certain stages of the illness.

Lung cancer is viewed as being composed of multiple stresses for patients and their carers and a number of multiple stepwise regression analyses and factor analyses support this view. These analyses suggest that one of the principle contributory factors to distress in the carer is distress in the patients and vice versa. In addition, the psychological state of the significant other combines with a range of other factors such as the amount and severity of symptomatology, personality variables, age and psychological adjustment to illness.

Of particular interest in this study was the role of perceived emotional social support in "buffering" or reducing distress in both patients and their carers. In patients, high levels of support were not found to be associated with reducing levels

of distress. In the carer, at certain stages of the illness, high levels of social support were associated with high levels of distress implying that social support might be stressful in itself. In the multiple stepwise regression analyses, perceived social support was found to contribute significantly to carer distress.

The concept of social support was found to be more complex than was previously thought and these results suggest that the multiple stresses imposed by lung cancer and its treatment cannot be reduced by the presence of a single type of social support alone. The implications of these results for service provision are discussed as well as the potential for future research in this area. In particular, the plight of the carer in lung cancer and the high levels of distress that they experience warrants further investigation particularly with a view to the implementation of psychosocial interventions.

DECLARATION

I declare that this thesis was composed by myself and that all data were collected and analysed by myself.

Signature

N. T. North

Date 27th September 1991.

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Chapter One

EPIDEMIOLOGY, AETIOLOGY AND TREATMENT OF LUNG CANCER.

Lung cancer presents a large and growing problem in the Western World. In 1989 it is estimated that there will be approximately 120,000 deaths from the disease in the United States of America, a rate of 70 per 100,000 (Loeb et al., 1984) and around 40,000 in the United Kingdom [Minna et al., 1985].

The incidence in Scotland is probably the highest in the world [HMSO, 1987]. In 1987, for example, there were approximately 4,290 deaths in Scotland due to lung cancer, a rate of 120 per 100,000 [OPCS, 1987], almost 50 per cent more than that found in the USA.

In Scotland the number of lung cancer deaths accounted for 7 per cent of the total number of deaths in the country in 1987 and represented almost 24 per cent of all cancer deaths [OPCS, 1987].

In the United Kingdom the incidence of the disease has increased every year and by 50 per cent over the last decade [Spiro, 1986]. Lung cancer is the leading cause of cancer death in men aged 35 years and older and the second leading cause of cancer deaths in women aged between 35 and 74 years of age, (after breast cancer), [Silverberg, 1984]. Recent years

however have seen a dramatic rise in the incidence of lung cancer amongst women. The male to female ratio in 1952 was 13:1, but by 1984 had risen to 4:1 [Loeb et al., 1984]. A number of more recent studies however have described a male to female ratio of 2:1 [Spiro, 1986]. Vincent de Vita [1985] in a seminal work on cancer and its treatment has hypothesised that lung cancer will replace breast cancer as the most common malignant disease in women by the end of the century.

A recent paper from the Edinburgh Lung Cancer Group [1987], reviewed 2,586 patients registered with the group between 1 January 1981 and 31 December 1984. Of this number 72 per cent were male and 28 per cent were female (2.5:1). These figures aptly demonstrate the change in the sex ratio for this disease which was discussed earlier. In the same study the age distribution of the patients was also representative of the overall picture found in the Western World. At the time of diagnosis 4 per cent of patients were aged under 50 years, 20 per cent were aged 50-59, 39 per cent were aged 60-69, and 36 per cent were aged 70 years and over. The median age was 66.8 years with a range of 23-94 years. Females in the study were significantly younger than the men with 79 per cent aged less than 70 compared with 61 per cent of the men; 7 per cent of the women were aged less than 60 compared with 3 per cent of the men. This data broadly supports the conclusion of the National Institute for Health over a decade ago in 1977 when they concluded that the disease is uncommon but not unknown before the age of 40 and the incidence is highest in

both sexes between the ages of 55 to 65 years of age. There is also a significant gradient in the incidence of lung cancer across social classes which is intrinsically linked to cigarette smoking.

Aetiological Factors

A number of aetiological factors have been implicated in lung cancer including exposure to radioactivity and radioactive minerals, exposure to asbestos, nickel, chromium, coal gas, metallic iron and iron oxides [Doll and Peto, 1981].

The most significant association has been shown to be with cigarette smoking. When tobacco was first introduced into Europe at the end of the sixteenth century, smoking was recommended for medicinal purposes; its use soon became controversial and it was condemned as a noxious vice as often as it was praised for its prophylactic value. Little scientific evidence was obtained about its adverse effects until the late 1940's. At this time medical textbooks either tended to ignore the subject completely or began referring to tobacco amblyopia, a form of blindness associated with heavy pipe smoking and poor nutritional status, to tobacco angina (a rare form of angina in which chest pain was precipitated by smoking), and to cancers of the lip and tongue, which experienced surgeons had, for many years, suspected were associated with the smoking of pipes.

In 1950 five papers appeared in the U.K. and the U.S.A. in which the smoking habits of large numbers of patients with cancer of the lung or, in some studies, with cancers of the mouth, pharynx or larynx were compared with the smoking habits of apparently healthy people [Doll and Hill, 1950; Levin et al., 1950; Mills and Porter, 1950; Shrek et al., 1950; and Wynder and Graham, 1950]. In the classic paper by Doll and Hill [1950], the authors concluded that "smoking is a factor, and an important factor, in the production of carcinoma of the lung". The results of these early studies proved to be the catalyst for a series of worldwide prospective studies which clearly demonstrated the association of smoking not only with lung cancer but also with a significant increase in overall mortality [United States Public Health Service, 1982].

Since the 1950's the increased publicity concerned with the adverse effects of smoking, coupled with the steadily increasing price of cigarettes has led to a decline in cigarette smoking both in the United Kingdom and the United States of America. In the U.K. cigarette consumption amongst men reached a peak in 1941 (4,420 cigarettes per adult male per year, or 12 cigarettes per day), and did not change materially until about 1973 (3,980 cigarettes per male adult per year, or 10 cigarettes per day). Thereafter it declined rapidly to 2,600 (7 cigarettes per day) in 1982 - a fall of 35 per cent and this pattern continues. Among women, however, cigarette consumption increased to a zenith in 1974 (2,630 cigarettes per adult female per year, 7 per day) and thereafter declined to 2050 (5 per day) in 1982- a decrease of 22 per cent. There

are fears now, however, that among women the number of smokers is increasing again [Vessey and Gray, 1985]. In the past five years in the U.K. the most rapid rate of decrease of cigarette consumption has been among the upper socioeconomic classes [Spiro, 1986]. It is currently estimated that 35 per cent of men smoke and about 36 per cent of women smoke, and a particularly worrying figure, despite health education, is the estimate that 25 per cent of children under the age of 15 in state schools smoke [Spiro, 1986].

A great deal of political debate has surrounded the demonstration of an association between cigarette smoking and lung cancer. Discussion has been concerned with such diverse aspects as cost of treatment, methods of health education, loss of tax revenue, reduction in productivity resulting from ill health, no smoking in public areas and the infringement of personal liberty. A confusing array of apparently contradictory points of view have been given a public forum in the popular press and media.

Internationally a wide variety of approaches have been adopted, aimed at the restriction of smoking. In many Scandinavian countries, for example, it is socially unacceptable to smoke in public places and dramatic rises in the cost of cigarettes are now beginning to produce a decline in smoking related illnesses. In Britain, however, the restriction of smoking in areas has been protracted and cigarette advertising still proliferates in popular magazines and journals. At present the British Health Education Council has an annual budget of

approximately half a million pounds to spend on its anti-smoking campaign, compared with an estimated seventy million pounds spent on advertising by the tobacco industry [Souhami and Tobias, 1986]. This discordant level of financial power has led to vociferous criticism of government policy from such organisations as Action on Smoking and Health (A.S.H.). These debates have had wide public exposure so that the smoker has been placed under enormous pressure to give up, a fact that may complicate reactions to a diagnosis of lung cancer.

In the U.K. lung cancer mortality is tending to follow the trend in cigarette consumption. As has already been mentioned lung cancer in women has increased dramatically and, indeed, continues to increase. The rate in women has more than doubled over the last thirty years [Wald, 1985]. This rise is particularly noticeable in the 55 years old and above age group [Wald, 1985]. Male lung cancer mortality on the other hand in England and Wales is declining in all age groups from 30 to 69 years [Wald, 1985].

Since the 1950's, many studies have examined the relationship between smoking and lung cancer; it is not appropriate, however, to discuss this past literature in detail here. Summarising this body of work, it has been found across studies that the risk of lung cancer increases with number of cigarettes smoked, with years of smoking, with earlier age at onset of cigarette smoking, with degree of inhalation, with tar

and nicotine content of cigarettes smoked and with use of filtered compared with non filtered cigarettes. In contrast to these factors it has been found that risk decreases with the number of years since smoking cessation.

A further factor which is worth comment is the issue of passive smoking. This has been given increasing attention during the past decade. A number of studies show an association between respiratory illness in young children and exposure to parents' cigarette smoke [United States Public Health Service, 1979]. In examining the effects of passive smoking in adults there have been major methodological problems in attempting to measure exposure in a non smoking adult partner of a smoker. This has resulted in the publication of equivocal results from research centres around the world and a great deal of controversy. Thus, the conclusions that can be drawn from these studies must be viewed with caution. They are, however, summarised in the following quote from the International Agency for Research on Cancer Working Group in 1986:

> "The observations on non smokers that have been made so far are compatible with either an increased risk from 'passive' smoking or an absence of risk. Knowledge of the nature of sidestream and mainstream smoke, of the materials absorbed during 'passive' smoking, and of the quantitative relationships between dose and effect are commonly observed from exposure to carcinogens leads to the conclusion that passive smoking gives rise to some risk of cancer." [IARC, 1986].

This discussion regarding passive smoking has been included because it is an issue which has been given increasing media coverage in recent years and may, therefore, present itself as an issue to patients diagnosed as suffering from lung cancer as well as to their relatives.

Lung cancer is also known to occur in non smokers but the incidence is very much lower than in smokers and is often related to occupational exposure to toxic chemicals.

Screening programmes for lung cancer aimed at early detection of the disease have met with very little success. They have been conducted in high risk groups such as smokers, at risk occupational groups (asbestos workers), and most importantly smokers in these occupational groups who run a very high risk of developing the disease. The rate of detection of lung tumours using 6 monthly chest radiographs has been poor and even when detection has been successful at an early stage this has not improved long term survival [Spiro, 1986]. Screening is therefore no longer recommended.

Pathology of Lung Cancer

There are four main histological type of bronchial carcinoma:

1. Squamous (epidermoid) cell carcinomas

This accounts for approximately 50 per cent of all lung cancers and is therefore the commonest type. These tend to present in the major bronchi as obstructing lesions.

2. Adenocarcinomas

This type of lung cancer appears to be less clearly related to cigarette smoking than other types of lung cancer as it was probably the predominant cell type before the advent of widespread cigarette smoking (Spiro, 1986). These tumours often originate in the periphery of the lung and may grow to a large size before giving rise to symptoms. Unlike other forms of lung cancer it is slightly more common in females and there is some evidence that it is increasing in frequency. It accounts for about 20 per cent of all lung cancers.

3. Small cell (oat cell) carcinoma

This tends to be a very rapid growing tumour which quickly spreads, if left untreated, invading blood vessels, the lymph system and soft tissues. They are often widely disseminated before symptoms are produced and a diagnosis is made. They also account for about 20 per cent of all lung cancer cases.

4. Large cell carcinomas

These tend to be bulky tumours and like the small cell type invade locally and disseminate widely. They are a less common type of tumour and account for about 8-10 per cent of all lung cancer cases.

For the purposes of this review and study, lung cancer will be considered as two major types of disease. Firstly, small cell

lung cancer and secondly, non small cell lung cancer which is a combination of squamous cell, adenocarcinoma and large cell carcinoma. The groups are considered in this way reflecting current clinical practice and treatment strategies among inoperable patients.

The Natural History of Lung Cancer

Small cell lung cancer is a disease which spreads rapidly so that by the time many patients are diagnosed the disease has already infiltrated other organs. The disease most commonly metastasises to liver, brain, bone, adrenal glands and abdominal lymph nodes. Untreated, death is rapid. The median survival from diagnosis is approximately five weeks for patients with extensive disease (i.e. having spread to organs other than the thorax) and twelve weeks for patients with limited disease (i.e. confined to one hemithorax), with only 4 per cent of patients still alive at one year [Hyde et al., 1965; Roswit et al., 1968; Zelen, 1973]. In a study by Nou [1984], of 50 patients diagnosed as having small cell lung cancer, none were alive at five years.

Non small cell lung cancer presents a slightly different picture. Nou [1984] in a sample of 223 untreated patients with non small cell lung cancer limited to the thorax, found a median survival of six months. In a similar study looking at patients with extensive disease Cormier et al. [1982], found a median

survival of 8.5 weeks with 100 per cent mortality at one year from diagnosis.

Hyde et al. [1973] examined a large group of patients with non small cell cancer of the bronchus. They found that the different subtypes of this disease had different survival times. Patients with adenocarcinoma of the bronchus survived longer than those with squamous cell or large cell carcinoma. The median survival for these three groups was 13 weeks, 9.5 weeks and 6.75 weeks respectively. This data, however, does not distinguish patients on the basis of the extent of the disease spread. In a similar study of 828 patients who did not receive treatment, Bangma [1963] reported that only 8 survived to three years (less than 1 per cent).

The effect of treatment on the survival time of both small cell and non small cell cancer of the bronchus will be dealt with later in this chapter.

Clinical Features

Patients presenting with lung cancer may have three types of symptoms: local (primary) symptoms; metastatic symptoms; and non metastatic extra pulmonary symptoms.

Local (primary) Symptoms

Patients most commonly present with chest symptoms, the most common being a flu like illness associated with a cough which affects about 80 per cent of patients. Other chest symptoms include haemoptysis (70 per cent of patients), dyspnoea (60%), chest pain (40%), wheeze (15%) and blood stained sputum. Patients may experience these symptoms for several weeks before consulting their doctor [Spiro, 1986].

Metastatic signs and symptoms

Intrathoracic metastatic spread and/ or distant metastases are present in up to 50 per cent of patients presenting with bronchial carcinoma [Hande, 1983] and in about 30 per cent of these cases the patient presents with symptoms caused by the metastases.

The symptoms of metastatic spread vary depending on the site involved and they may include respiratory, cardiac or neurological problems. The disease may spread to a wide range of vital organs sometimes presenting a complex array of symptoms. Patients often present with non-specific features such as weight loss, anorexia, or lassitude which are indicative of the presence of occult metastases.

Extra-pulmonary symptoms

A number of abnormalities may occur in other organ systems as a result of the primary tumour in the lung. For example,

about 12 per cent of patients develop endocrine abnormalities, extreme weight loss of several stones may occur as well as blood disorders and vascular problems, any of which may prompt the patient to visit their doctor.

Asymptomatic presentation

Approximately 5 per cent of patients with primary bronchial carcinoma are diagnosed on routine radiography. These patients may have no symptoms at all and the tumour may be found by chance at an "annual check up", for example.

On the other hand, they may present to their family doctor with what the patient may regard as minor flu like symptoms and then following further investigation be presented with a diagnosis of lung cancer: a disease with an extremely poor prognosis and relatively short duration.

Investigation

Before the patient can be fully informed of the diagnosis, prognosis and potential treatment options, a series of investigations must be performed to determine the type of tumour and the extent of spread.

The patients will undergo various chest X-rays taken from different angles to examine the size of the tumour. They will then undergo a bronchoscopy which is the passage of the fibre optic tube into the lung. This enables the direct visualisation of

the tumour but also enables samples of tissue to be taken in order to establish a histological diagnosis.

The extent of the spread of the tumour may be assessed using a variety of investigative techniques; bone scans, brain and liver scans and mediastinoscopy are all used to investigate the spread of the disease. Based on the results of these investigations treatment options can be considered by the patient and his/her doctors.

Treatment

The principles of treatment of small cell and non small cell lung cancer are different. Small cell lung cancer is seldom surgically resectable, usually it is widespread at presentation and is both more chemosensitive and radiosensitive than non small cell lung cancer. For these reasons the treatment options will be considered separately.

Small cell lung cancer

The majority of patients present with extensive disease. That is disease involving more than one hemithorax or with metastatic spread. This means that surgery is rarely, if ever, an option for patients with small cell cancer of the lung.

Chemotherapy

Because this type of lung cancer spreads rapidly due to the rapidly dividing cells, it is sensitive to cytotoxic drugs. In fact it is more sensitive to chemotherapy than any other lung cancer type. Early studies using a single drug found that the median survival in patients was raised from 5 weeks to 12 weeks for patients with extensive disease [Bergsagel et al., 1972; Broder et al., 1977; Bunn et al., 1977]. During the late 1970's and early 1980's, however, it was demonstrated that combinations of drugs were superior to a single agent [Smyth et al., 1986]. Combinations of three or four drugs tend to be favoured as the anti tumour effects are increased. However, the toxic side effects experienced by the patient are more prononounced.

In patients with limited disease treated with combination chemotherapy, median survival improves from three months to fourteen months. Approximately 10 per cent of patients remain disease free for two years and later relapse after this period is uncommon, but still can and does occur [Morstyn et al., 1984]. In recent years, attention has centred on identifying those patients who would benefit from this approach, and in so doing increase the numbers of long term survivors. In patients with extensive disease, a group with a very bleak outlook, median survival improves from about 5 weeks to about 8 months with around 5 per cent of patients still alive at 2 years [Morstyn et al., 1984]. The aim of treatment here is to obtain maximum relief from the disease with a minimum of toxicity.

These apparently modest gains in median survival are achieved at some cost in terms of treatment side effects resulting in a great deal of controversy concerning the optimal balance of quantity versus quality of life (which will be addressed in a later chapter).

Radiotherapy

Small cell tumours in the lung are extremely radiosensitive and a disappearance of the tumour on X-ray is seen in about 80 per cent of patients. Although the initial response to radiotherapy is usually gratifying, recurrence of the tumour is frequent. A British Medical Research Council trial demonstrated that radiotherapy extended median survival time to 11 months but that less than 4 per cent of patients lived to 5 years [Fox and Scadding, 1973].

Radiotherapy is of great palliative value in small cell lung cancer and is the treatment of choice for painful metastases to the bones and for metastases of the brain. Radiotherapy can give swift relief for these distressing symptoms with a minimum of side effects [Souhami and Tobias, 1986].

Non Small Cell Lung Cancer

Surgery

For non small cell lung cancer, surgical resection of the tumour offers the best hope of 'cure', but less than 30 per cent of

patients will be suitable for this. Of those patients who do undergo surgery, however, 80-85 per cent will survive at 5 years [Martini and Beattie, 1977] and even in the patient with more advanced disease a five year survival rate of 50-60 per cent can be achieved [Williams et al., 1981]. Despite the good results achieved through surgical treatment in the early stages, the overall 5 year survival rate for this disease is very poor (less than 4 per cent) [Huhti et al., 1981].

Radiotherapy

Although patients with non small cell lung cancer have always formed a large part of the work of the radiotherapist, there is continued debate regarding the indications for its use. The majority of patients presenting with non small cell cancer of the bronchus are unsuitable for radical radiotherapy, the aim in these patients is to palliate their symptoms.

If, however, all locally inoperable lung cancer patients are irradiated with curative intent, median survival time is only slightly prolonged: a 4 per cent increase in one year survival, compared with untreated patients [Roswit et al., 1968]. In highly selected subgroups of patients, five year survival rates of 10 per cent can be obtained, which is more to do with better patient selection than improved radiotherapy [Cox et al., 1983].

When radiotherapy is used to palliate the symptoms of non small cell lung cancer, immediate clinical benefit may be produced but this approach does not prolong life. In a study by Durrant et al. [1971], radiotherapy, chemotherapy or a

combination of both were compared to a group of patients receiving no treatment at all. The survival time was the same in both groups, yet radiotherapy proved to be superior in palliating patients with specific symptoms such as severe cough or pain.

Therefore, despite the fact that the palliative potential of irradiation in this form of lung cancer is beyond doubt, and despite its potential to achieve a 'cure' in a very small number of patients, the employment of radiotherapy has not led to an improvement in the overall survival in lung cancer.

Chemotherapy

Approximately 50 per cent of patients with non small cell lung cancer have distant metastases at the time of diagnosis and another 40 per cent will develop locally recurrent or distant spread of their disease following initial treatment with surgery or radiation therapy [Hande and Malcolm, 1983].

Reviews of chemotherapy in non small cell cancer of the lung have demonstrated that regimens using multiple drugs are no better that those that employ single agents [Bleehen, 1980]. Recent reports using the very toxic drugs cisplatin in combination with etoposide indicate a possible therapeutic benefit compared to other combinations [Sculier and Klastersky, 1984], these findings, however, have yet to be confirmed in controlled clinical trials. This combination did,

however, produce a median survival of 12 months in this particular patient group, a finding still to be replicated.

Although combination chemotherapy can produce responses in this disease, its impact on survival has not been convincingly demonstrated in a sufficiently large number of patients from different institutions under different clinical conditions [Hansen and Rorth, 1984]. It has been claimed that:

> "if any 'progress' has been made in the treatment of non small cell lung cancer with combination chemotherapy, it is too small to be measured in clinical trials using survival as an end point and also too small to justify the use of chemotherapy in the routine treatment of non small cell lung cancer."[Bakker, 1986, p26].

A damming statement concerning the treatment of this disease with cytotoxic drugs

Conclusion

This chapter summarises the situation which faces a patient who has a diagnosis of lung cancer. The patient may have developed some symptoms, a cough or wheeze and consulted his or her general practitioner. Further tests will have revealed the tumour and the histological type of that tumour. These results, coupled with possible referral to an oncologist, then indicates therapeutic options available to the patient, the family and the doctor. Thus the patient and the family may be presented with the diagnosis, the various treatment options and perhaps the appalling prognosis. Given this picture, it is

not surprising that many patients are devastated first of all by the word "cancer" but also by the information that accompanies this concerning therapy and survival.

Studies describing the psychosocial sequelae of these events will be critically reviewed in the chapters that follow, dealing with both patients and their families.

Chapter Two

THE PSYCHOLOGICAL IMPACT OF CANCER ON THE PATIENT

Much of the research conducted in the area of psychological impact of cancer on the patient has been concerned with breast cancer and its treatment [Maguire, 1976; Maguire et al., 1978]. The body of literature concerned with psychosocial aspects of cancer of the breast is vast, stretching back over many years. This literature has proved to be very helpful in highlighting the psychosocial sequelae of a life threatening illness but is limited in its application to other types of cancer.

Cancer is a complex disease; it has many forms and consists of many stages. The literature concerning breast cancer contains methodological problems which make this simple statement difficult to appreciate. The disease has specific implications regarding sexuality, body image and body function [Maguire, 1984]. It is also predominantly a disease of women. These facts alone make it difficult to use the findings from research in this area to make generalisations about other forms of cancer especially lung cancer which is still predominantly affects males and is concerned with an internal vital organ.

The methodology of this literature is also lacking in that many research studies concentrate on a single point in time, often not specified and often not linked to disease related variables

[Freidenbergs, 1981-82]. These criticisms limit the usefulness of this body of work. This chapter will deal with literature of a more general nature investigating aspects of other types of cancer. Where appropriate research in the field of breast cancer will be utilised but this field will not be reviewed independently in this thesis.

The structure of this literature review will be to portray cancer as a life threatening disease consisting of stages and therefore "a process". This "process" will be shown to consist of so called "normal" reactions and "abnormal" reactions mediated by various factors. The findings of various studies will be shown to be be limited and inconclusive due to the research methodology employed which include poor research design and a reliance on opinion rather than hard data.

Cancer as a "process"

To a medical practitioner the concept of an illness as a process is obvious. In the field of psychosocial oncology research, this has not been apparent. Few researchers have addressed this question and, in consequence, little data exists concerning the psychological impact of cancer at different stages of the disease.

Weisman [1979] and his colleagues from the Omega Project in Boston, postulated that an illness such as cancer could be conceptualised as consisting of a "process" or a trajectory along which the patient progresses. This "process" commences at the

time a label is applied to the patients' symptoms i.e. the point of diagnosis and continues through treatment, post treatment, palliative treatment to death or in some cases cure.

Accompanying the physical dimensions of the disease, were the psychological sequelae and psychological adjustment, which occurred over time, in tandem with the physical changes. This concept of "the process", therefore, was important in imposing a framework on the experience of the patient.

Weisman devised a model to relate psychosocial events in the cancer patient to their clinical and therapeutic counterparts. This model proposed by Weisman is shown in Figure 1 with the psychosocial events superimposed on the clinical events.

Figure 1:

PSYCHOSOCIAL PHASES OF CANCER

PHASE I EXISTENTIAL PLIGHT

DIAGNOSTIC IMPACT

PLIGHT PROPER

PHASE II ACCOMMODATION AND MITIGATION

ORIGINAL TREATMENT ONLY

RESPONSIVENESS (+)

RESISTIVE (-)

FOLLOW UP TREATMENT

RESPONSIVE (+)

RESISTIVE (-)

PHASE III RECURRENCE AND RELAPSE

RELAPSE DURING PHASE II TREATMENT

RESPONSIVE (+)

RESISTIVE (-)

RECURRENCE AFTER PHASE II TREATMENT

RESPONSIVE (+)

RESISTIVE (-)

LIMBO (NO ACTIVE TREATMENT)

PHASE IV DETERIORATION AND DECLINE

PALLIATIVE TREATMENT

SUPPORTIVE MEASURES ONLY

DEATH WATCH -TERMINALITY

PHASE I Existential Plight

The first stage of this model was described by Weisman and Worden [1976-77]. It begins with the diagnosis and continues in its extreme form for about three or four months, approximately 100 days. This entity was described by the authors in a descriptive study of 120 patients with a range of different types of cancer. They were interviewed and followed up from ten days after diagnosis at four to six week intervals until three to four months had elapsed. This study is shown in Figure 2.

FIGURE 2

Existential Plight: 100 Days.

Patient Group	No Subjects	Variables	Tests
Breast Cancer	37	Coping	Interview
Lung Cancer	23	Vulnerability	MMPI
Colon Cancer	23	Support	TAT
Hodgkin's Disease	18	Personality	POMS
Melanoma	19	Mood	

(MMPI = MINNESOTTA MULTIPHASIC PERSONALITY INVENTORY, TAT = THEMATIC APPERCEPTION TEST, POMS = PROFILE OF MOOD STATES)

The patient group completed a range of tests and a semi structured interview to collect demographic data and assess mood disturbance, personality traits, coping concerns, vulnerability, and support. The tools used were standardised

assessment scales except for the semi structured interview which was devised by the researchers.

The results of this study are difficult to interpret due to their vague unsatisfactory presentation. It is not clear, for example what treatment patients are receiving, the degree of symptomatology they are experiencing or how they were selected. It is, however, clear that patients with lung cancer were significantly more distressed as a group than the other diagnostic categories during the study period. During the first 100 days following diagnosis the distress in lung cancer patients rose steadily. They were less concerned about family, friends and religion than about existential, work and personal health matters. In contrast, the distress levels of patients with Hodgkin's disease diminished during the study period. This difference presumably reflects the poor therapeutic response and appalling prognosis facing patients with lung cancer.

The chief preoccupations of the patients with lung cancer during this period of "existential plight" were concerned with life and death, health and physical symptoms such as pain and breathlessness. The most vulnerable groups of patients in this study were those who were widowed or divorced and those who anticipated little or no support from significant others.

Although the concept of existential plight is useful, the study itself contains a number of methodological weaknesses. The study period was only four months so that it is difficult to ascertain the duration of the "existential plight" and whether it

is affected by the experience of treatment. It also appears that in certain types of cancer, for example, lung cancer, the period of initial distress is still increasing at the end of the study time. Finally, some of the tools used to assess function such as coping concerns and vulnerability were developed by the researchers and no figures for their validity or reliability were given, making it difficult to judge the factors that are actually being measured.

Distress as measured by the profile of mood states, was found to be high at diagnosis and persisted at this level for at least three months.

PHASE II ACCOMMODATION AND MITIGATION

Weisman describes the beginning of this second phase, following the completion of treatment, or at a point when the patient returns to a more routine life. It is a phase concerned with a broad range of adaptive efforts and tactics for alleviating or coming to terms with residual effects of cancer. Weisman does concede that the time period at which this phase may begin may vary enormously: for some patients their initial treatment may last two months; for others the period of therapy may be considerably longer. Also, patients may require additional treatment, for example surgery followed by radiotherapy or chemotherapy followed by radiotherapy.

According to Weisman, this second phase is a period of optimism following treatment but also a period of low level anxiety due to the continued monitoring of disease status by the physicians and the constant surveillance that the patient subjects himself or herself to. This surveillance is a period in which the patient assesses physical signs and symptoms for any indications of the return of the disease.

PHASE III RECURRENCE AND RELAPSE

For many patients, their disease returns or spreads either during treatment (relapse) or at some point after treatment (recurrence). Often more treatment is given but with lower probability of success. During this phase, reassurance for the patient may be difficult. Optimism, high morale and according to Weisman even denial are extremely difficult to maintain. The challenge to accommodation and mitigation is that earlier treatment and probably the most effective treatment has failed.

Phase III can, therefore, be viewed as a secondary existential plight even though another remission may be possible. This is the phase of pessimism and vulnerability often leading to a state referred to by Weisman as "limbo" for the patient. Following this period more moderate expectations may be employed by the patient so that the hoped for "cure" may be replaced by desire for respite, control and extra time.

PHASE IV DETERIORATION AND DECLINE

Weisman claims that during the time referred to as "limbo" patients "are inclined to become more passive and compliant, as if realizing that there are fewer options and less time"(p192). The deterioration may be abrupt or insidious and at some point in this process palliative treatment may be instituted to alleviate troublesome symptoms.

According to Weisman, psychosocial problems during this time become more apparent as deterioration progresses. There is "unfinished business" to be dealt with and a feeling in patients that time may be short. As symptomatology worsens, then the issue of death looms large for many patients and psychological problems may ebb and flow depending on the severity of the symptoms.

Whilst this concept of psychosocial phasing is difficult to substantiate and the methodology of Weisman and Wordens' research problematic, the concept of an illness as a "process" is an important and useful one. It helps to indicate periods of potential distress and also suggests that research in the area of psychological impact of cancer on the patient should attempt to capture this dynamic pattern. Such a process would start when the patient suspects their diagnosis (before it is established) and progress until death or many years following "cure".

How and when does adjustment take place?

The revelation of the diagnosis of cancer is inevitably traumatic and devastating. Patients may experience a range of emotions regarded as "normal" and others which are regarded as "abnormal" such as clinical anxiety and depression. Patients probably begin a process of psychological adjustment before a firm diagnosis has been made when they are experiencing various symptoms which prompt them to consult a doctor. The information imparted thereafter and their appraisal of the threat of the disease dictate their emotional reaction to the stresses.

Aitken-Swan and Paterson [1955] found that the majority of patients with breast cancer suspected their diagnosis before it was confirmed. This is further supported by studies examining delay in seeking a medical opinion. Approximately 25 per cent of women may delay up to three or four months before consulting their general practitioner regarding a lump in the breast [Green, 1976; Margarey et al., 1977]. The principal reasons given for such delay were fear of diagnosis and fear of treatment and its effects [Green, 1976]. (Coping strategies and their relationship to adjustment to be discussed in detail in Chapter 5 in relation to Social Support.)

Normal reaction to a diagnosis of cancer

The revelation of the diagnosis of cancer creates its own psychological sequelae. Lloyd et al. [1984] interviewed 40

patients within two weeks of being given their diagnosis of lymphoma. Patients in this study were examined using the standardised psychiatric interview and a number of visual analogue scale measuring pain, anorexia, nausea, fatigue, general health, concern and hopelessness.

The study revealed that in the two weeks following diagnosis, 15 of the 40 patients (37.5%) could be regarded as experiencing clinically significant psychiatric morbidity. In this group of patients depression and anxiety were the predominant symptoms, the content of these being concerned with the implications of the tumour on future health and life expectancy. The remainder of the patient group scored within the normal range on the standardised psychiatric interview, but most showed some degree of distress at being given their diagnosis. Nevertheless all of the patients approved of having been told this information and favoured an open approach to communication.

Senescu [1964] has identified several categories based on certain fundamental reactions to disease:

1. The dependency response: Complex prolonged investigation and treatment tend to make a patient dependent on the medical services. This may provoke two extremes of response: either a complete loss of initiative and responsibility so that the patient comes to rely totally on the medical and support services for all his needs; or a struggle to retain total independence as the need for reliance on others is seen as humiliating and threatening.

2. Loss of self esteem: This involves the feeling or belief that having cancer is a major physical imperfection and that one is irreparably damaged as a result.

3. Anger: As an anticipatory response to actual or threatened pain or damage. This may be non specific and directed against fate or the "unfairness of it all" or focussed on a particular aspect of the disease or treatment or even an individual.

4. Guilt: This may exist in addition to other responses and may have many sources. This may include the belief that the disease is some form of punishment for a previous wrongdoing or misdemeanour, thereby invoking a feeling guilt.

5. Loss of gratification: the patients can no longer enjoy previous pleasures and withdraws into a state of total lack of interest in outside stimuli.

The stress reaction resulting in the patient when the diagnosis of cancer is confirmed is similar to that seen in victims of other types of trauma [Horowitz, 1979]. Falek and Britton [1974] have postulated that this type of psychological disturbance is a necessary process leading to readjustment and can therefore be viewed as appropriate and normal. During this period of early adjustment, the patient experiences many conflicting emotions of numbness, disbelief, anger, protest, fear, hope and despair [Renneker and Cutler, 1952; Sutherland and Orbach, 1953; Bard and Sutherland, 1955;

Peck, 1972]. It can be a time of emotional turmoil and disorganisation. Patients may see their world as fragmented and uncertain and issues regarding death, which up until this point have been avoided may be thrust upon them. Part of the stress reaction has been said to invoke a desperate attempt to give sense and meaning to a "disintegrated " world [Weisman and Worden, 1976-77]. The idea, however, that these emotional reactions follow a particular sequence with fixed stages through which everyone must pass is highly questionable [Silver and Wortman, 1980].

Within the time span of a few days, a patient can progress from the suspicion of cancer to the firm diagnosis and beginning of treatment. The reactions occurring at this time are responses to the stress which is most salient at any given time. For example, in breast cancer the stress response pre-operatively is predominantly related to the loss of the breast, one of anxiety, with insomnia and difficulty in concentrating on routine matters - a response to the uncertainty of the situation. Following treatment the stress response may be a preoccupation with every ache or pain in the body as the patient is preoccupied with the possibility of recurrence [Maguire, 1976].

The very word "cancer" produces fear in the patient on a number of levels, leading to a feeling of disorganisation. As previously described, the threat of death looms large, but there are also uncertainties concerning the future, fear of pain, fear of disfigurement, disability and loss of function, fear of

losing family and work and a feeling of stigma and alienation [Spikes and Holland, 1975; Holland, 1975]. This initial period following diagnosis is characterised by features such as anxiety, insomnia, irritability and poor concentration. The acute phase is thought to resolve when a feeling of alliance with the doctor(s) occurs and a treatment plan is initiated. In so doing, the patient feels that some degree of "control" is being exerted over the situation [Holland, 1973].

When cancer recurs

The literature concerning the psychological impact of cancer following the initiation of treatment is sparse, particularly, when considering the range of "normal" reactions.

Facing a diagnosis of cancer is a time of reappraisal of priorities and of life itself but the occasion of recurrence of the disease may be a time of even greater psychological stress. Silberfarb et al. [1980] found that feelings of depression and anxiety were more frequent in the patients at a time of recurrence than in the terminal stage of the illness. For many patients the disease does not respond to treatment but in the case of recurrence, the disease has disappeared (or is at least undetectable) and the patient may believe that they are "cured". The reappearance, therefore, of the tumour may result in a catastrophic reaction on the part of the patient and their relatives. The lack of systematic literature with respect to this aspect of psychosocial oncology makes it difficult to

draw any firm conclusions and is an area where more research would be extremely valuable.

The terminal phase

The "normal" reactions in the terminal phases of an illness have likewise received scant attention. Linn and Linn [1986] state that "fear of death or death anxiety, is present in all people to varying degrees, and there is nothing abnormal about it". They continue to acknowledge that clinical states such as anxiety and depression exist in the terminal stage of an illness but that dying itself is not a psycho-pathological process. Linn and Linn [1986] describe dying as something which takes place over time. A view adapted from the work of Glaser and Strauss [1968] who developed the concept of the "dying trajectory". Glaser and Strauss demonstrated that the term "dying" in the context of a disease such as cancer is a social construction. To be regarded as "dying", the patient must fall within some set of circumstances as defined by the staff. Once patients had been given this label then staff unconsciously "managed" their interactions with the patient in such a way as to exert control over how much patients were aware of their own condition and how much patients could express of their awareness [Glaser and Strauss ,1965].

Kubler-Ross [1969] has described fully the phases that dying patients go through. Much of this work is based on observation and has not been subjected to more rigourous scrutiny. Other researchers in this area have found that the dying patient

does not fear death as much as the process of dying [Cramond, 1970]. This is borne out by more recent studies which have found that patients' fear the possibility of a painful lingering death. Symptoms of pain, weakness, anorexia and the loss of functions such as bowel and bladder control, lead to major functional limitations which can be frustrating and humiliating for the patient [Bukberg et al., 1984].

Kastenbaum and Aisenburg [1972] have found that with diminishing physical capabilities, the dying patient wants to talk, keep communication open and have a part in the management of his death, while the taboos of death and its discussions may isolate fatally ill patients so that they are unable to realise these goals. This dichotomy, the researchers claim, isolate the patient and further heighten his fear and anxiety.

Once again, the literature in the area of "normal" reaction to the terminal phase of cancer is sadly lacking and opens a number of avenues for useful research.

Those who "survive"

The final part of this discussion concerning the psychological impact of cancer during the illness process is concerned with "survivors".

The psychological effects of long term survival have only recently been examined. Having been diagnosed and treated

for the disease and been forced to face one's own mortality, the survivor may experience a tenuous sense of longevity. This may produce feelings of anxiety, depression, damaged body image, and of course fears of recurrence of the tumour. This has been termed the "Damocles Syndrome" [Koocher and Malley, 1981] and has been likened to an anticipatory grief reaction reported in the families of patients dying from prolonged illness [Futterman and Hoffman, 1973]. Patients may show difficulties in effecting the transition from "patient" to "healthy individual". The reactions displayed in this situation include decreased stamina, social estrangement and job insecurity. At the same time the person may be vividly reminded of their former illness by continued hospital follow-up appointments and difficulties in obtaining new employment or taking out health insurance [Stone, 1975; Wheatley et al.,1974].

In general, however, distress has been found to decrease with time from diagnosis, affording the survivor greater emotional distance from the acute traumas of diagnosis and active treatment [Kennedy et al., 1976; Li and Stone, 1976; Mages and Mendelsohn, 1979]. It must be recognised that the term cancer encompasses a wide spectrum of different diseases invoking different treatments, potential outcomes and factors such as age at diagnosis. Because of this a number of former patients may demonstrate that distress can increase with time since diagnosis either because of the gradual lifting of psychological defences against distress or because of the

intensification of stress associated with potential re-entry into the patient role [Polivy, 1977].

A final perspective in this area is that some former cancer patients appear to experience significant existential gains in life experience from the cancer experience, arising from confrontation with mortality (diagnosis), sickness and struggle for health (treatment) and, finally, illness free survival. They show no major psychopathology and in fact have better levels of adjustment than non-patients [Craig et al., 1974; Kennedy et al., 1976; Cella and Tross, 1986].

The variety of responses seen in survivors reflects the wide range of disease and biographical factors that are influential on the psychology of the cancer patients.

Positive psychological changes

A minority of patients have been found to derive marked psychological benefit from their experience of suffering from cancer. Even though these patients may be entering the terminal phase of the disease having not responded to treatment they say that the experience of the illness has changed their lives for the better. The enhancement in life quality in these patients has been found to be due to a realisation of priorities in life, fulfilling long standing ambitions and formulating plans and ideas to augment the life available to them. These patients also report improved relationships with people and a feeling akin to euphoria whilst

still accepting the gravity of their situation [Kennedy et al., 1976; Roud, 1986; Hughes, 1987]. This positive aspect of the disease must be treated with caution as it only applies to a small number of patients and must not be confused with denial which will be discussed later in this chapter.

"Abnormal" reactions to a diagnosis of cancer

A large part of the research carried out in the field of psychosocial oncology is concerned with "abnormal" reactions to the disease. This literature encompasses such reactions as depression, anxiety, denial and more generalised emotional disturbance. Despite the large number of published papers in this area, the majority fail to address the concept of the illness as a process and therefore tend to use single assessments of the psychological state of the patient using heterogeneous groups of patients at different stages of their illness and do not acknowledge this fact when presenting their results. This often makes interpretation of the data difficult in terms of comprehension for the reader and in assessing the applicability of the findings. The literature also often fails to elucidate the severity of these "abnormal" reactions so that the reader is not able to discover if the effect is so severe that it warrants psychiatric intervention. This is partly due to the plethora of assessment tools that have been used by various studies. Many of these tools do not give levels of "caseness" for psychological disorder and others are instruments that are not standardised and therefore have poor reliability and validity making interpretation difficult. This applies particularly to

assessment scales that have been developed for use with psychiatric patients and contain somatic items relating to anxiety and depression. In the field of oncology these somatic items serve merely to confuse the issue as factors such as weight loss or loss of appetite are features of a disease such as cancer and therefore cannot accurately be attributed solely to a diagnosis of depression [Maguire, 1984].

Perhaps the most valuable contribution in this area has been made by Maguire and his colleagues in Manchester. They have laid the theoretical foundations by studying the psychiatric problems of breast cancer patients over a five year period [Maguire, 1976; Maguire et al., 1976a; Maguire et al., 1978]. This type of study then led to further studies by these researchers with a variety of different cancer patient groups but also prompted other people to carry out similar studies in other parts of the world. This early work has influenced and continues to influence most of the subsequent research conducted in this area of psychosocial oncology. It was Maguire who first drew attention to the problems of cancer patients suffering from an affective disorder.

Depression

Studies of the prevalence of psychiatric disorder in adult cancer patients suffering from leukemia, Hodgkin's disease, lymphoma, melanoma or sarcoma have found that up to one in four patients develop an anxiety state, depressive illness or mixed affective disorder [Craig and Abeloff, 1974; Plumb and Holland, 1977; Davies et al., 1986]. This statement although

apparently easy to comprehend in this bold form, fails to take into account the numerous methodological and theoretical problems that exist in this area of psychosocial oncology.

In these studies different criteria have been used to make a diagnosis of depression. Some have used self report inventories to assess its incidence such as the SCL-90 [Craig and Abeloff, 1974] or the Beck depression inventory [Plumb and Holland, 1977] whilst others have used clinical interviews by researchers or psychiatrists [Perrin and Pierce, 1959; Fraser et al., 1967; Levine et al., 1978]. This variety of assessment methods makes comparison of the data across studies very difficult, even when standardised tools such as the Beck depression inventory and the SCL-90 are used, we have no knowledge concerning their comparability. A further problem in the use of these tools is the inclusion and weight given to somatic items, which, as described earlier may confuse the diagnosis of depression in the cancer patient.

The stage of disease is another problem in this literature as many studies will use a group of patients at different points in the illness process. Jaffe et al. [1986] for example present data on a group of 21 patients with pancreatic cancer but give no indication of when they were diagnosed, what treatment they have had or the severity of their physical symptoms.

Depression identified in patients may be a transient stress reaction rather than a depressive illness. Maguire [1984] makes the point that it is important to distinguish the severity

and duration of symptoms when assessing psychopathology in cancer patients. Plumb and Holland [1981], in an elegant study looking at patients with advanced cancer, found that the levels of depression varied depending on which assessment scale was used. They also found that the numbers of patients identified as "depressed" varied according to whether it was a single assessment of the here and now or whether the patients had experienced significant depressive symptoms during the preceding 30 days [Plumb and Holland, 1977; 1981]. The final criticism of research in this area is the often unproven assumption that depression in cancer patients is related to the diagnosis of cancer. Peck [1972], for example, found that 27 of 50 patients were diagnosed as having a psychiatric disorder, and in all but one of these it antedated their current medical illness. Peteet [1979] in reviewing the assessment of depression in cancer patients concludes that "depression among patients with cancer is a prevalent clinically important although not universal phenomenon that may or may not be primarily related to the diagnosis and prognosis of the cancer itself"(p1489).

Perhaps the most extensive study looking at the prevalence of depression in cancer patients was conducted by Derogatis et al. [1983]. In this study 215 cancer patients undergoing active treatment for their disease were assessed using a formal psychiatric interview, the SCL-90, and the Raskin Depression Screen (a self report rating scale). Forty four per cent of the patients assessed manifested a recognised clinical psychiatric

syndrome and of these 13 per cent diagnosed as suffering from a major affective disorder.

Studies looking at the prevalence of depression of patients with lung cancer are of particular interest in this review, but there are few reports to date. Hughes [1985a] assessed 134 lung cancer patients at diagnosis using a combination of a self assessment questionnaire and a structured clinical interview with specific criteria for the assessment of depression. 16 per cent of this group of patients fulfilled the criteria for a depressive illness. 58 per cent of the depressed lung cancer patients, however, gave a clear history of having been depressed before their physical symptoms began, apparently in reaction to life stress unrelated to the illness. The prevalence of depression in the patients with lung cancer was higher than in a comparison group of patients with benign chest disease, a sample of patients attending hospital without serious illness and a sample of people from the general population. Hughes found that the most significant correlates of depression in the cancer patients were a past history of psychiatric illness and the presence of metastatic disease.

Hughes then followed up these patients 2-3 months after diagnosis and re-assessed then using the same assessment tools [Hughes, 1985b]. In this study 50 patients were included in the study. Of this group 16 per cent fulfilled the criteria for depressive illness. This was a lower prevalence then that recorded of the time of initial presentation when 26 per cent of the same patients had been depressed. Eight of the 13 who

were depressed originally had recovered, five had remained depressed and three new cases of depression had arisen. Hughes found that the patients who had not received any active treatment were more likely to be depressed than those patients receiving either radiotherapy or chemotherapy.

Cella et al. [1987] in a different type of study investigated the relationship between a general concept of psychological distress, extent of disease and performance status in 455 patients with lung cancer. Psychological distress was measured using the Profile of Mood States (POMS), which gives a measure of mood distress. This group of researchers were not attempting to measure "caseness" but the effect of disease related variables on distress.

The study found that there was a statistically significant association between the extent of physical impairment and mood disturbance. There was also an interactive effect with the extent of disease so that the increase in mood disturbance seen in patients who have a more impaired physical status is more pronounced for patients with extensive disease.

These two papers form the body of knowledge of the psychological impact of lung cancer. A further study by Silberfarb et al. [1983] (to be discussed later) examines the impact of chemotherapy for lung cancer on psychological response. Obviously many studies using heterogeneous samples of cancer patients will include lung cancer in their samples but do not analyse these patients separately.

Other factors besides the extent of physical impairment have been found to contribute to affective disorders in cancer patients. Symptomatology, such as pain, breathlessness, weight loss and fatigue which could be regarded as an aspect of physical disability, has been found to raise the prevalence of depression. Hinton [1963], for example, found that 40 per cent of terminally ill cancer patients with pronounced symptoms were depressed in contrast to 20 per cent of patients where symptoms were not a feature.

Sex differences have also been investigated. Leiber et al. [1976] found that in a variety of cancer types, female patients were more depressed than male patients with a similar diagnosis. Findings such as this must be treated with caution, however, because other evidence suggests that women may be more willing to disclose their problems and feelings of low mood even though the men may be experiencing this type of distress [Kennedy et al., 1976].

A previous history of psychiatric problems has been reported as predicting the development of depressive illness in cancer patients. This has been reported with such groups of patients as breast cancer [Maguire, 1982], lung cancer [Hughes, 1985a], and advanced leukemia and Hodgkin's disease [Plumb and Holland, 1977; 1981].

The lack of a confiding relationship has also been found to increase the vulnerability of people experiencing a wide range

of stressful life events not just life threatening disease [Brown and Harris, 1978]. Maguire [1982] found that the presence of a confidant was a protective factor against developing an affective disorder.

A central theme throughout this thesis is the importance of looking at an illness such as cancer as a "process" rather than a single event in time. Maguire and his colleagues have conducted a study which gives a picture of a proportion of this "process". They investigated the psychiatric problems of breast cancer patients over a five year period. Results indicate that psychiatric morbidity is the highest in the first year after diagnosis. Data derived from 75 women with breast cancer were compared with that of fifty women with benign disease one year after initial diagnosis. It was found that 25 per cent of the cancer patients were in need of psychiatric treatment [Maguire et al., 1976a]. Morris et al. [1977] continued to study the psychological and social adjustment of these same type of patients over a two year period. Results indicated that two years after diagnosis, whilst 71 per cent of cancer patients were no longer distressed, 22 per cent had significant depressive symptoms. This study clearly shows that in the early years following diagnosis of breast cancer patients experience significant psychiatric morbidity.

The studies described and discussed in this section demonstrate that despite methodological problems in its assessment, depressive illness does occur in cancer patients. The changing pattern of depression throughout the course of

the disease has not been described fully but the prevalence it appears, is known to be higher in patients with more advanced disease, increasing levels of physical disability and symptoms and the incidence is also higher in those patients with a previous psychiatric history.

Anxiety

The same methodological problems that have been discussed in the assessment of depression can be applied to the assessment of anxiety states in cancer patients.

Maguire et al. [1978] found that about 20 per cent of women were at risk of developing an anxiety state in the early period following a diagnosis of breast cancer. Derogatis et al. [1983] found that of their 215 mixed cancer patients, 4 per cent were diagnosed as having an anxiety disorder and approximately 85 per cent of these patients with a positive psychiatric condition were experiencing a disorder with depression or anxiety as the control symptom.

Devlen et al. [1987b] in a prospective study of 120 patients newly diagnosed as having Hodgkin's disease and non-Hodgkin's lymphoma found that 36 per cent of the group exhibited symptoms of anxiety and depression. In fact, during the first three months following diagnosis anxiety was the most common psychiatric disorder found. In the 61 patients who exhibited psychiatric symptoms, 73 per cent suffered from an anxiety state [Devlen et al., 1987a]. These researchers found that although the incidence of symptoms of anxiety was

the same as in breast cancer patients the incidence of symptoms of anxiety was considerably lower. The conclusion of the authors is that this "may reflect the better prognosis of lymphomas"(p957). It was also striking that although the initial level of anxiety was high after the diagnosis was made these states resolved once the patients had been given a clear account of their diagnosis and treatment. This demonstrates the importance of information in helping patients to make an appraisal of the threat and thereafter develop appropriate coping strategies as time progresses.

Davies et al. [1986] studied 38 patients with a malignancy of the head and neck. Patients were assessed before they underwent a biopsy and therefore before they had had the diagnosis confirmed. This group of patients were compared to an identical group of patients undergoing investigation for a head and neck tumour but whose lesion had turned out to be benign. The number of patients who experienced a clinical level of anxiety (pre diagnosis), as defined by the Leeds assessment scale was comparable, 40 per cent in the malignant group and 41 per cent in the benign group. The level of depression in the malignant group (pre diagnosis), on the other hand, was double that of the benign group. Unfortunately the design of this particular study makes it impossible to explain the marked difference between the two groups in terms of depression. The data does demonstrate that any sort of diagnostic investigation is likely to lead to elevated anxiety levels, even in those patients who are subsequently found not to have a malignant neoplasm.

A number of studies have highlighted factors which can lead to higher or lower levels of anxiety. Symptoms, and in particular pain and breathlessness have been found to elevate levels of anxiety in cancer patients [Gibbs and Achterberg-Lawlis, 1978]. In the terminal phases of the illness patients who reported having a sense of fulfilment in life had better adjustment and lower anxiety levels [Hinton, 1975] and prior experience with the death of a close friend or relative (due to illness), have been found to offer the individual the chance to develop a healthy understanding of death before having to face his or her own. This experience has been found to lead to lower levels of death anxiety and fear in cancer patients [Gibbs and Achterberg-Lawlis, 1978; Carey, 1974a]. There is also some evidence to suggest that individuals claiming religious affiliation have lower levels of anxiety following diagnosis [Breugel, 1971; Carey, 1974b; Yates et al., 1981].

Anxiety, like depression is a significant problem for cancer patients. There are methodological problems in its assessment and the pattern of anxiety throughout the course of the illness has not been described fully. Anxiety is evident before a firm diagnosis is established and is heightened by investigation and symptomatology. It is, however, responsive to information concerning treatment and prognosis and its prevalence appears to be related in certain circumstances to the site of the tumour.

Denial

Denial is concerned with defence against overwhelming anxiety. It is a psychoanalytic concept which covers a wide range of phenomenon rather than being an all or nothing entity. Patients may minimise, ignore or completely reject evidence of disease or its significance.

Denial and its assessment is a controversial area in psychosocial oncology as there is considerable evidence that in certain situations denial is adaptive [Hamberg et al., 1953; Hacket et al., 1968; Hackett et al., 1969; Hackett and Cassem, 1970] and may prolong life [Hackett et al., 1968]. Where denial results in delaying medical consultation and the start of treatment [Aitken-Swan and Paterson, 1955; Gold, 1964; Greer, 1974], it is clearly maladaptive, increasing the risk of morbidity and probably mortality. Denial may inhibit communication between family members who adopt different coping strategies creating serious emotional problems between patients and their relatives [Stedeford, 1981].

Methodological critique

Cancer is a complex disease; it has many forms and goes through many stages following diagnosis. The study of the impact of the disease on the patient and concomitant adjustment is thereby complicated by the difficulties inherent in studying the disease process. There are various methodological problems in the literature on this subject that make comprehension difficult. Familiarisation with this body

of literature does not necessarily result in an understanding of the psychological impact of the disease on the patient. The methodological shortcomings of this literature have already been alluded to earlier in this chapter but can be broadly summarised thus:

1. **Clustering cancer patients as a single group:** Many studies take a heterogeneous group of cancer patients and study them as if they represented a single disease entity [Derogatis et al., 1983; Farber et al., 1985]. Consequently such factors as site of cancer, staging of the disease and prognosis are not examined or reported. This merely serves to cause confusion in interpreting the findings because as discussed earlier factors such as site of disease or stage of disease may be important in the adjustment process. These factors therefore must be considered in the design of any study in psychosocial oncology.

2. **Demographic factors:** these factors must be considered when examining the impact of cancer. Factors such as age [Craig and Abeloff, 1974; Plumb and Holland, 1977], religious affiliation [Yates et al., 1981] and previous psychiatric history [Maguire, 1982] have been found to be important in the adjustment to cancer. Most studies routinely record the age of the patient group but other demographic variables are often ignored.

3. **Assessment of psychiatric disorders:** statements concerning the psychosocial impact of cancer are often based

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on a test score. This raises a number of issues. Firstly, any tests used should be standardised, valid and reliable. Certain studies have employed unstandardised tests or unstructured interviews from which the authors infer "caseness" [Schmale and Iker, 1966a; 1966b]. Secondly, any tests used must have been developed for use with physically ill patients. Studies employing scales originally devised for use with psychiatric patients may give erroneous results due to the presence of somatic items included in them [Koenig et al., 1967]. Thirdly, papers reporting the prevalence of psychiatric disorders may use tests that do not detect "caseness" such as the MMPI [Koening et al., 1967]. This makes comparison difficult, as the raw scores from the numerous scales and interviews used in the literature are not easy to equate. This in turn, complicates issues such as planning and evaluating appropriate psychological interventions. For example, Hughes [1985a; 1985b] used a psychiatric interview, Davies et al. [1986] used the Leeds self assessment scales, Devlen et al. [1987a] used the present state examination, Jaffe et al. [1986] used the schedule for affective disorders and Plumb and Holland [1977; 1981] used the Beck depression inventory. Finally control groups or even comparison groups of patients have often not been used [Perrin and Pierce, 1959; Fox, 1978] and it is therefore difficult to place these results in any type of framework or context.

These methodological problems need to be addressed, therefore, when considering psychiatric disorders in cancer patients. A more rigorous approach to assessment needs to be

taken and the psychometric properties of any scales used must be carefully considered.

4. Opinion and anecdote: whilst many studies have used test scores to examine the psychosocial impact of cancer, others have used unstructured interviews and anecdotes [Hinton, 1963; Hackett and Weismann, 1969; Holland et al., 1977; Leigh et al., 1980; Brooks, 1985; Forester et al., 1985]. Plumb and Holland [1977] have drawn attention to this difficulty and have commented that terms such as "depression", "denial" and "anticipatory grief" are not operationally defined and that data are not provided on the reliability of response classification. Furthermore, not only is it important to reliably report the presence of a phenomenon, but it is equally important to know who is making the determination. Different judges may view the same phenomenon differently, resulting in discordant findings [Worden and Weismann, 1977; Slevin et al., 1988].

5. "Process"; many of the studies in the field of psychosocial oncology do not take into account the fact that the disease can be seen as a process. Frequently, studies use a "snapshot" technique, assessing patients on a single occasion [Peck, 1972; Koenig et al., 1967]. Whilst Maguire and his colleagues have attempted to look at changes in the psychological state of patients during the five year period following diagnosis of breast cancer, this approach is almost unique in the literature. The concept of the disease as a "process" is axiomatic to medical practitioners, but is a major omission in research

studies conducted by those working in the area of psychosocial oncology.

Future studies in this area must address these methodological shortcomings in order to develop a complete and coherent picture of the psychological impact of cancer on the patient. Assessment must be made at different stages of the disease with valid and reliable instruments in specific cancer types.

Chapter Three

THE PSYCHOLOGICAL IMPACT OF TREATMENT FOR CANCER

Cancer treatment consists of three principal modalities: surgery, chemotherapy and radiotherapy. Patients may receive one or a combination of these treatment modalities depending on the type of cancer that they suffer from. The treatments often have physical side effects, such as hair loss, nausea, vomiting, loss of a limb or disfigurement depending on the modality. In addition to these physical side effects, however, a considerable body of knowledge has been developed relating to the psychosocial sequelae. Much of this literature relates to breast cancer where patients may experience all three treatment types over the course of their disease. This literature will not be reviewed extensively due to the highly specific nature of breast cancer and its treatment but reference will be made to it, in order to demonstrate methodological points and deficiencies in the literature relating to cancer treatment as a whole. In addition, the psychological sequelae of surgery will not be reviewed as only a very small number of patients with lung cancer undergo this treatment approach. (In the current study no patients had surgery for their disease.)

Radiotherapy

Radiotherapy is a commonly used treatment option for many types of cancer. Numerous studies have reported psychological reactions as a result of this type of therapy. Peck [1972] used

psychiatric interviews to study the affective reactions of 50 cancer patients with varying sites of disease who were undergoing radiation treatment. He found that anxiety (98 per cent of the sample) and depression (75 per cent) were common.

In a further study, 50 patients interviewed before and after their radiation treatment [Peck and Boland, 1977] demonstrated that 62 per cent of the patients were depressed and 66 per cent were anxious pre-treatment. However, 22 per cent of the patients had a continuing psychiatric disorder which began well before they had cancer. Following treatment, 80 per cent of patients exhibited a mild or moderate anxiety state and 74 per cent a mild or moderate depressive illness. Other reactions noted by the psychiatrist were irritability (36 per cent), suspicion (30 per cent) and euphoria (10 per cent).

The second interview took place at the end of treatment when radiation reactions, both systemic and local are at their peak. The authors conclude that these reactions undoubtedly augment pre existing anxiety and depression and that the increase in psychological problems are a result of the treatment rather than the knowledge of the diagnosis.

Forester et al. [1978] administered a modified version of the Schedule for Affective disorders to 200 cancer patients with different cancer types. These questionnaires were administered at the beginning, midpoint, and conclusion of radiotherapy, and again two weeks following the completion of

treatment. The scores of the cancer patients were then compared to those of 84 psychiatric patients.

The results demonstrated that although the patients undergoing radiotherapy were depressed and anxious, their levels of distress were significantly lower than the psychiatric comparison group. In order to determine if the type of radiation treatment was associated with differentially elevated negative affect scores, the scores derived from the 100 patients who received betatron therapy (large loud machine; daily treatment of two to three minutes) were compared with those derived from 100 patients receiving linear acceleration therapy (a small quiet machine; daily treatment of two to three minutes). It was found that as radiotherapy continued the intensity of anxiety and depression symptomatology decreased among patients treated with the linear accelerator while they increased in patients treated with betatron. The authors conclude that certain aspects of the treatment employed are associated with psychological distress.

Andersen and Tewfik [1985] conducted an elegant study of 45 mixed cancer patients undergoing radiation therapy with curative intent. The study was designed to determine individual differences in psychological responses to treatment. Patients were divided into those with high, moderate, and low levels of anxiety at the start of treatment using the Spielberger State Trait Anxiety Inventory.

The results revealed that patients with an initial high level of pretreatment anxiety reported a significant reduction in their state anxiety, although at post treatment follow up they remained the most anxious subgroup. Patients with a moderate level of pretreatment anxiety reported little change in their state anxiety responses. Finally, patients with low levels of anxiety prior to radiation therapy reported significant increases in state anxiety at post treatment such that they equalled the state-anxiety level maintained by the group with moderate pretreatment anxiety.

The authors suggest in their conclusion that the expression of moderate fear or distress may have substantial benefits for cancer patients. It may begin to herald the beginning of an adaptive type of "worry" which may include attending to information concerning treatment, accepting reassurances from others and coping with feelings of helplessness. All such responses may facilitate adjustment to the treatment process.

The moderate level of anxiety at the end of treatment may be indicative of a level appropriate to a life threatening illness like cancer. It may be anxiety that can facilitate adaptation should further treatment be required for the patient's disease.

This data demonstrated that the concept of anxiety related to the treatment of disease is not as straightforward as has been postulated in earlier studies. It is clear that the pretreament level of anxiety may be important in the patients later adaptation and further research is required to describe the

patterns of psychological response to treatment given at a later time in the disease process.

Chemotherapy

Chemotherapy consisting of combinations of drugs often have severe side effects such as nausea, vomiting, hair loss and a wide range of other sequelae such as skin rashes, sore throats and secondary infections [De Vita, 1985]. Many studies examining the psychological impact of chemotherapy have used women undergoing treatment for breast cancer as subjects [Maguire et al., 1978; Morris et al., 1977]. This data is highly specific and is therefore difficult to apply to other types of cancer treatments. The data is complicated further by the fact that the subjects in these papers may have undergone a mastectomy as well as cytotoxic chemotherapy. More recently a number of papers have been published in which patients have been able to choose their own treatment types [Ashcroft et al., 1985; Steinberg et al., 1985; Morris and Ingham, 1988; Margolis et al., 1989]. Patients described in these studies may undergo chemotherapy in particular treatment regimes and the element of choice appears to play a role in mediating psychological distress [Ashcroft et al., 1985], although in studies where no choice is available high levels of psychiatric distress have been reported in patients receiving chemotherapy, in the order of 38 per cent [McArdle et al., 1981]. Maguire et al. [1980], conducted a randomised clinical trial of breast cancer patients treated with mastectomy plus a combination of chemotherapy drugs versus treatment with

mastectomy alone. In the group of patients receiving the combination chemotherapy it was found that 81 per cent suffered from psychiatric morbidity (anxiety and depression) requiring treatment, compared with 50 per cent receiving surgery only. The psychiatric sequelae were particularly evident in those patients who experienced the more severe forms of drug toxicity.

Studies of a more general nature, however, have been conducted. Silberfarb et al. [1980a] studied 50 consecutive patients with a variety of cancer types admitted to a medical oncology ward and treated with chemotherapy, radiotherapy or nothing. On tests of cognitive function, 35 per cent of those receiving chemotherapy were found to have deficits compared to only 4 per cent of patients not receiving chemotherapy. Interestingly, none of the patients in this study were found to have significant levels of anxiety or depression.

Devlen et al. [1987b] assessed 120 patients with Hodgin's disease and non-Hodgkin's lymphoma. Patients were treated using a combination of cytotoxic drugs. It was found that episodes of depression lasting from one to three days occurred at the administration of treatment. In total, 25 (21 per cent) of the sample experienced such episodes with the majority receiving one particular treatment regimen (this included the drugs mustine,vinblastine, prednisolone and procarbazine).

Lloyd et al. [1984] found similarly high rates of anxiety and depression before and during treatment. These authors did not

find an elevation of psychiatric symptomatology during the course of chemotherapy however. Love et al. [1989] investigated the impact of treatment side effects on emotional distress in a sample of 238 patients undergoing treatment for breast cancer or lymphoma.

Patients were interviewed at five points during their first six cycles of therapy. The side effects most frequently reported were hair loss, nausea and tiredness and each of these was experienced by more than 80 per cent of patients at some time during the six cycles of treatment. In addition, vomiting, sleep disturbance, weight gain, mouth sores and numbness/ tingling were a consequence for more than 40 per cent of the sample.

Interviews were conducted with patients to assess emotional distress. The interview was unstandardised and inter-rater reliability was calculated at 80 per cent between four raters. 90.3 per cent of patients reported some degree of emotional distress from chemotherapy as assessed by a ten point scale. Higher levels of distress were reported as treatment progressed and a highly significant correlation was found between the number and severity of the side effects and the level of emotional distress. The side effects of treatment were severe enough to prompt 46 per cent of patients to have considered stopping therapy by the final cycle of treatment, yet only three of the total patients group discontinued treatment, against the advice of their physician.

This paper contains numerous methodological flaws both in the use of unstandardised assessment tools and in the use of a heterogeneous group of cancer patients, but it is useful in that it relates patients' emotional distress over time to treatment related effects.

Gilbar and Kaplan de-Nour [1989] in a refinement of the previous study examined factors which led to a dropout from chemotherapy. These researchers put forward the hypothesis that the presence of severe treatment side effects would not be sufficient to cause patients to discontinue treatment, but that they would demonstrate a number of other symptoms of maladjustment.

Gilbar and Kaplan de-Nour matched 53 cancer patients who had dropped out of chemotherapy with 53 patients who had completed treatment. Patients were assessed using the Psychosocial Adjustment to Illness Scale (PAIS) and the Brief Symptom Inventory (BSI).

The results demonstrate clearly that those patients who dropped out of chemotherapy exhibited more adjustment problems in a number of areas of life functioning. The patients who dropped out also had significantly higher levels of psychosocial distress than those completed treatment. The psychosocial difficulties experienced by those patients undergoing chemotherapy are not simply due to the side effects imposed on them by the treatment but are a much more complex interaction between emotional distress,

treatment side effects, feelings, thoughts and perceptions of treatment. Indeed, a number of other studies have demonstrated that increased emotional distress is not simply related to the number and severity of side effects and extent of the disease but is probably the result of the interaction of physical, psychological and social variables [Davies et al., 1973; Silberfarb et al.,1980a; Schmale et al., 1982-3].

Cain et al. [1983] examined some of the complexities of this relationship. Sixty women were studied within one month of being diagnosed with cervical, uterine and ovarian malignancies. The women were assessed using the Hamilton Anxiety and Depression Rating Scales and the Psychosocial Adjustment to Illness Scale.

The authors found that the scores of all the patient groups (cervical, uterine, and ovarian malignancies) demonstrated the presence of mild depressive symptomatology. The symptoms of depression however in women receiving triple agent chemotherapy and, therefore, having a higher level of side effects and physical symptomatology approached the level typically obtained by people entering outpatient psychiatric clinics. On closer inspection of this group, however, it was found that these women exhibited less knowledge of their illness and treatment than other women, had a significantly lower level of education and demonstrated a poorer adjustment to their illness generally. The authors conclude that these women with higher levels of depression suffer from a much greater disruption of "social role function" which when

interacting with the increased level of side effects and physical symptoms could lead to greater levels of psychological distress.

Other studies have tried to refine the factors implicated in adjustment still further. Silberfarb et al. [1983] investigated the effects of specific chemotherapy regimens in patients. Seventy seven patients with small cell lung cancer were randomly assigned to two regimens. Depression and fatigue were assessed in the patients using the Profile of Mood States questionnaire.

The results of the study showed that one regimen produced a greater degree of depression and fatigue than the other. This effect could not be accounted for in terms of tumour reduction as there was no difference between the two groups in terms of tumour response. The major difference between the two treatments was that one contained the agent vincristine, a vinca alkaloid known to cause disturbances in the biogenic amines in the brain. The vinca alkaloids have been reported to block the transport of dopamine beta hydroxylase which is responsible for converting dopamine to norepinephrine [Poisner and Bernstein, 1971; Van Praag, 1982]. Changes in this neuro-transmitter are thought to affect mood, leading to depression. Therefore, the authors speculate that the regimen containing vincristine was responsible for the higher level of depression than the treatment without the drug.

A number of other anti cancer drugs have been investigated in the same way. Adams et al. [1984] examined ten patients with metastatic renal cell carcinoma receiving treatment with human leukocyte interferon alpha therapy. The majority of the patients exhibited severe behavioural changes such as psychomotor retardation, social withdrawal and decreased energy as well as mild to moderate cognitive, affective and personality changes, particularly in the first week of treatment. A finding more recently replicated by McDonald et al. [1987] in a group of patients receiving alpha interferon for chronic hepatitis B infection.

Other compounds that have been investigated in a similar way include L-asparaginase [Holland et al., 1974], vinblastine [Peterson and Papkin, 1980], mechlorethanine [Calabresi and Parks, 1975], methotrexate [Bleyer, 1977], fluorouracil [Greenwald, 1976] and steroids [Ling et al., 1975].

Another aspect of treatment that must be taken into account when considering the psychological impact of cancer is that of nausea, vomiting and the anticipatory aspects of this.

Chemotherapy induced nausea and vomiting

The pharmacological side effects of cancer chemotherapy are extremely varied. Gastro-intestinal side effects particularly nausea and vomiting have been reported as being the most noxious. Coates et al., [1983] in a study examining patients perceptions of the side effects of chemotherapy found that

being sick and feeling sick were reported as being the most severe side effects.

These side effects usually begin one or two hours following chemotherapy and last for six to twelve hours although in some patients they may last for several days. These pharmacological side effects are usually treated with anti-emetic drugs such as metoclopramide; however, such drugs do not control nausea and vomiting in all cases and may have unacceptable side effects of their own such as drowsiness, diarrhoea and extrapyramidal symptoms [Gralla et al., 1981; Allan et al., 1984; Warrington et al., 1986].

One of the results of this chemotherapy induced nausea and vomiting can be conditioned effects [Burish and Carey., 1986]. They can occur before, during, or after chemotherapy treatment. When they occur before the treatment they are usually referred to as anticipatory side effects. When they occur during or after the treatment they are often intermixed with (and are difficult to distinguish from) pharmacologically caused nausea and vomiting. Conditioned side effects can be as aversive as pharmacological side effects, and once they develop they are usually refractory to medical intervention.

These psychological side effects are believed to be relatively common and develop through a process of classical conditioning. In a study conducted in Sweden by Olafsdottir et al., [1986] it was found that anticipatory nausea occurred in 40 per cent of patients and 14 per cent showed anticipatory

vomiting. Following the completion of four cycles of chemotherapy these numbers had increased so that 47 per cent experienced anticipatory nausea and 49 per cent experienced anticipatory vomiting.

These symptoms can be extremely distressing for patients so that some patients eventually discontinue chemotherapy (and therefore abandon hope for remission and cure rather than suffer such discomfort). Wilcox et al. [1982] studied 52 women receiving adjuvant chemotherapy for breast cancer. They reported that 27 per cent of the patients discontinued the adjuvant chemotherapy and 71 per cent of those who discontinued cited nausea and vomiting as the major reason for stopping. Of those patients who had terminated treatment because of nausea and vomiting, 70 per cent had experienced anticipatory vomiting.

A number of reviews of this aspect of chemotherapy have shown that these extremely severe side effects can in many instances be prevented or ameliorated using psychological techniques [Redd, 1982; Burnish and Carey, 1986; Carey and Burish, 1988]. In addition, it is not uncommon for patients to become depressed as a result of these disabling, conditioned effects, particularly when they do not understand the causes of this phenomenon [Carey and Burish, 1988].

"Quality of life"

In recent years more attention has been focussed on the impact of the illness and its treatment on specific areas of life functioning. The has led to a rapid increase in the literature concerned with defining and measuring the "quality of life" in cancer patients [Najman and Levine, 1981].

There appears to be no agreed definition of the term "quality of life" [de Haes and van Knippenberg, 1985] although it clearly involves concepts of physical and psychological well being. This lack of a clear definition has created problems in the design of tools to measure it. A number of approaches however have been developed.

The most commonly used index developed to measure "quality of life" is the Karnofsky Performance Index [Karnofsky and Burchenal, 1949]. The scale consists of ratings from 0-100 which take account of the presence of symptoms, the ability to carry out work and physical activity and self care. Whilst this scale is frequently used and has been influential since its inception its reliability has been questioned by several authors [Hutchison et al., 1979] and its validity as a "quality of life" measure has been a controversial issue [Clark and Fallowfield, 1986].

Researchers and clinicians have tried to develop more comprehensive scales capable of measuring more than just physical well being and also able to detect changes over time.

The Functional Living Index: cancer scale (FLIC) is one such tool [Schipper et al., 1984].

This scale is composed of 22 items. Each item is assessed by a graded linear analogue scale which give a measure of physical and psychological function and is therefore regarded as a "quality of life" index.

A number of other scales exist which have been labelled "quality of life" measures. Scales such as the Q-L index [Spitzer et al., 1981], the Barthel Index [Mahoney and Barthel, 1965] and the Rotterdam Symptom Checklist [de Haes et al., 1986].

Numerous scales exist purporting to measure "quality of life" but each has methodological and psychometric problems primarily due to the lack of definition of the concept. This area is comprehensively reviewed by de Haes and Knippenberg, [1985], Aaronson and Beckman, [1987] and Kind, [1988].

A different perspective on this problem has been to develop tools to examine the impact of an illness and its treatment on different areas of patients lives. One of the most comprehensive scales developed in this area has been the Psychosocial Adjustment to Illness Scale [Morrow et al., 1978]. The scale examines a patients' global adjustment to an illness and its treatment in seven principal psychosocial areas or "domains". These domains include: health care orientation; vocational environment; domestic environment; sexual

relationships; extended family relationships; social environment and psychological distress.

The instrument is not solely concerned with an attempt to define and measure quality of life but is fundamentally concerned with "adjustment" to illness.

Recent years have seen an increased emphasis on the concept of "quality of life" particularly in diseases such as lung cancer where increasingly toxic therapies are being administered to patients and where there is little chance of long term survival [Leonard, 1989].

Bakker et al. [1986] used the Karnofsky Performance Index as a measure of "quality of life" in 28 patients with non small cell lung cancer receiving combination chemotherapy. Patients who responded to treatment were compared with patients who did not respond (i.e. did not experience a decrease in tumour size). It was found that the "quality of life" measure dropped significantly during chemotherapy among responders and non responders and after discontinuation of treatment approached pre-treatment scores in responders only. The authors conclude that "treatment-associated toxicity and deterioration of the patients' well-being offset any potential survival advantage for the majority of patients."

One of the shortcomings of the above study is that the "quality of life" measure was stopped following the cessation of

chemotherapy thus leaving a significant part of the illness process unaccounted for.

Minet et al. [1987] used the same assessment scale to compare patients with non small cell lung cancer receiving radiotherapy alone with those receiving radiotherapy and chemotherapy. The authors evaluated the "quality of life" of patients every month from initial randomisation for treatment until death or the last follow up clinic before death.

In this study the authors found no statistically significant difference between the median survival of the two groups of patients. However, in terms of "quality of life", the group of patients receiving both chemotherapy and radiotherapy experienced a "better outcome" in terms of quality of survival during and after treatment.

In other studies, authors have developed their own questionnaires to answer questions concerning the "quality of life" advantage of treatment regimens. Kaasa and Mastekaasa [1988] and Kaasa et al. [1988] developed a ten question index which they refer to as the "psychosocial well-being questionnaire" to measure psychosocial well-being, medical side effects, physical function and everyday activity. This scale has been utilised in two studies comparing patients with non small cell lung cancer undergoing treatment with either combination chemotherapy or radiotherapy alone. In these two studies [Kaasa and Mastekaasa, 1988; Kaasa et al., 1988] it was found that the total well-being index score was

significantly higher in patients receiving radiotherapy than in patients receiving combination chemotherapy during the period of treatment. No differences, however, in the "quality of life" were detected in the follow up period of 52 weeks.

The most recent studies addressing this question have again use "quality of life" measures to assess the efficacy of different treatments. Fernandez et al. [1989] combined the Karnofsky Performance Index with a number of visual analogue scales. They studied 31 patients with advanced non small cell lung cancer and found that prior to therapy the entire group considered themselves to have a significantly reduced "quality of life" as a result of their illness. Following treatment however 75 per cent of this group reported improvement from their pre-treatment level.

The Medical Research Council Lung Cancer Working Party [1989] reported a multi-centre trial in the United Kingdom that compared patients with small cell lung cancer randomly allocated to either combination chemotherapy and radiotherapy started at diagnosis and selective treatment of radiotherapy or chemotherapy only started when it was necessary to control symptoms. This study utilised a diary card completed every day by the patients during the first six weeks of treatment. This assessed vomiting, activity, mood, anxiety and overall condition. Compliance with this approach, however, was poor and it became necessary to use a "quality of life" measure based on assessment by a physician at each clinic visit.

The results demonstrated that the policy of immediate treatment led to a longer survival time and a better "quality of life" as assessed by the clinicians. However, the data from the patients diary card demonstrated a worse "quality of life".

Despite the methodological problems of assessing "quality of life" this latter study demonstrated that it is important to make some measure of the impact of an illness and its treatment on the patient and, that the patients' view is extremely important as it may be at odds with the view of the physician. A view shared and demonstrated by Slevin et al. [1988] who found that "doctors could not adequately measure the patients' quality of life.....Quality of life is a concept that includes many subjective elements, and it is therefore perhaps not surprising that a doctor may not have the necessary knowledge of the patients feelings to assess their quality of life accurately"(p110). This is confirmed by more recent work in lung cancer. Physicians were found to be poor judges of the "quality of life" of a patient at presentation, as time from diagnosis increased, however, physicians improved in their assessment of the change in specific aspects of a patients' illness. This included aspects such as changes in physical symptoms and overall physical condition [Regan et al., 1991]. These authors while stressing the importance of the assessment of "quality of life", particularly in clinical trials suggest that the perceptions of both the physician and the patient need to be taken into account.

The importance of this concept in any study of the psychological impact of an illness and its treatment is further elucidated by Schipper and Levitt, [1985]."To the extent we are unable to prevent disease, the ultimate goal of medicine is to effect a cure and return the patient to a life-style not diminished by the illness and its treatment. The scientific power of modern medicine provides the biologic rationale to intervene with a force never before possible. The rigorous application of quality of life assessment is neither unscientific nor in competition with basic medical science as we know it. It merely serves to emphasize that the proper study of mankind is man"(p1122).

The psychological impact of treatment on the patient: a methodological critique

The methodological problems inherent in studying the psychological impact of treatment for cancer in many ways parallel those described at the end of Chapter 2 which considered the psychological impact of cancer on the patient.

1. Heterogeneous groups of patients

Studies often describe the psychological sequelae of a particular treatment modality using patients with varying types of cancer [Peck, 1972; Forester et al., 1978; Anderson and Tewfik, 1985; Silberfarb, 1980a]. The difficulty in interpreting this type of study is that different cancers often have a very different prognosis and a very different presentation [DeVita, 1985]. This makes accurate comparison

of these patients difficult despite the fact that they may receive the same treatment modality.

It is important, therefore, in planning future studies to consider the use of a homogeneous group of patients with one particular type of cancer undergoing a particular type of treatment. The value of this approach has been aptly demonstrated in studies conducted in the field of breast cancer [Morris et al., 1977; Maguire et al., 1978] where the impact of a disease entity and its treatment have been clearly described.

2. Treatment intent

The intent of treatment i.e. whether it is curative of palliative may be an important factor when considering the psychological impact. Many studies [Peck, 1972; Peck and Boland, 1977; Silberfarb, 1980a] do not specify either the intent of treatment or the patients understanding of this intent. A study assessing patients during different phases of treatment would be important in illuminating the patients reaction at these times and would separate out the psychological sequelae of treatment intent.

A further consideration in investigating treatment aims would be to preserve the concept of a treatment "process".

3. Side effects

The significance of treatment side effects on the psyche have been demonstrated in previous studies in the field of psychosocial oncology [Davies et al., 1973; Cain et al., 1983; Gilbar and Kaplan de Nour, 1989]. Future studies must be prepared to examine the effects of specific drug regimens and specific side effects such as nausea and vomiting as it is important to be able to disentangle the relative contributions of physical, psychological and social variables when considering the impact of cancer.

4. "Quality of life"

The concepts of "quality of life" has gained considerable importance in recent studies in oncology, despite the problems of definition and assessment. In view of the difficulties inherent in utilising the plethora of scales and questionnaires in this area researchers have turned their attention to assessing adjustment to an illness and its treatment and the impact of that illness on the patients' life [Morrow et al., 1978]. In order to understand more fully the complexities of the psychosocial impact of an illness and its treatment, it is important to undertake this type of assessment, particularly at different stages of the disease/ treatment "process".

Methodological concepts such as those outlined above must be considered in designing future research studies using valid,

reliable tools to describe fully the experience of the cancer patient at different points during the treatment process.

Chapter Four

THE PSYCHOLOGICAL IMPACT OF CANCER ON THE FAMILY.

Cancer presents a dilemma for the patient and his or her family. Cassileth and Hamilton [1979] have referred to it as a "family disease" with immediate impact on family functioning, roles, relationships and because of the potential for loss. The diagnosis, Cassileth and Hamilton postulate "reverberates throughout the family system."

The patients' family play two distinct and potentially contradictory roles during the illness and its treatment. They function as the patients first line of emotional support and are so perceived and encouraged by health care professionals [Regan, 1965; Giacquinta, 1977]. Simultaneously, and paradoxically, they are viewed along with the patient as the unit requiring care and therefore equally in need of attention and support [Huth, 1978]. In fact it has been postulated that the position in which family members find themselves when a member develops cancer is even more stressful than in the patient [Dyk and Sutherland, 1965].

It is surprising, therefore, that the area of impact of cancer on the family of the adult cancer patient has been largely neglected. The patient has been the focus of research into

psychosocial oncology and the family has on the whole been the subject of personal opinion and anecdotal case reports.

These reports often acknowledge the importance of the family as a whole in cancer care, yet few of the authors continue to study the impact on the family in any systematic way although, papers are often concluded with a hypothetical plan for future research in this direction. Sheldon et al. [1970] state "the patient, in addition, remains a part of an ongoing family unit that must live with the disease and an indefinite sentence of death"(p744). Freidenbergs et al. [1981-82] in their major review of psychosocial oncology claim that "unfortunately, there are few studies documenting the actual psychosocial impact of cancer on either the patient or his/her family"(p304). Naysmith et al. [1983] in a further review conclude, "there is surprisingly little data regarding family interactions while an adult member of the family deals with cancer"(p26). Cassileth et al. [1985], in one of the most important research studies in this area concludes that, "additional assessment of this kind is required to document relationships between patients' and their relatives' emotional status and to methodically assess the psychosocial status of relatives"(p72).

Many studies, however, examine the effects on the family of diagnosis and treatment of cancer in children [Lansky and Cairns, 1978; Spinetta et al., 1981; Spinetta, 1982; Monaco, 1986]. In general, these studies have been conducted from a

family therapy or developmental perspective which does not have immediate relevance for this review.

The illness as a "process"

Cancer and its treatment can be viewed as a "process", not only for the patient but for the family also. Giacquinta [1977] has developed a model consisting of "stages" and "phases" for the systematic description of the functioning of family members. This model consists of ten phases of family functioning within four stages. This model is shown diagrammatically in Figure 3.

Figure 3.

Phases and stages of family functioning in cancer care (Giacquinta, 1977).

Points of Transition in Individual with cancer	Family Stage	Family Phase
Individual receives initial diagnosis of cancer, continues to carry out role obligations with the family and functions in varying ways as a family member	Living with cancer	i. Impact ii. Functional disruption iii.Search for meaning iv.informing others v. engaging emotion
Individual with cancer ceases to perform familiar roles and is cared for either at home or in hospital	Restructuring in the living dying interval	i. Reorganisation ii. Framing memories
Individual with cancer dies	Bereavement	i. Separation ii. Mourning
	Re-establishment	Expansion of the social network

This concept was based, according to the author, on an analysis of 100 families coping with the diagnosis and treatment of

cancer. This conceptualisation is consistent with the literature previously reviewed in Chapter 2 which demonstrated that the patient with cancer experiences different phases of an "illness trajectory".

Giacquinta [1977], unfortunately, presents no data from the analysis of 100 families to explain the development of this model of phases and stages. It is,however, quoted extensively by a number of authors in reviews of 'cancer and the family [Freidenberg et al., 1981-2; Northouse 1984; Cassileth et al., 1986; Lichtman and Taylor, 1986].

Despite the support for this model of family functioning in the field of psychosocial oncology, research endeavours to date have not attempted to validate the notion of a "process" with respect to the family.

The small body of literature concerning the family of the adult cancer patient can be divided into two types; anecdotal/discursive and 'scientific' or empirical.

Anecdotal/discursive literature

This type of literature consists of either observations of a single case or the personal view of a particular author. The papers are often emotionally laden and are not based on the results of research studies or any theoretical perspective. This approach often has strong support, but because of the way in

which it is generated its usefulness in terms of application is difficult to ascertain.

Worby and Babineau [1974] for example, describe a family interview technique that encourages them to "verbalise suppressed feelings". This approach, the authors speculate will help the "family adjust to the impending death". In this paper, sections of dialogue are reported and the conclusions are based on the authors observation rather than on any objective end points.

Similarly, Snee [1979] discusses, at some length, her own views concerning the support needed by the families of cancer patients. Whilst this approach has obvious face validity and is written with care and sensitivity the article is based on a number of broad generalisations that need to be evaluated and examined in a more rigorous manner before they are put into clinical practice.

A common approach in this body of literature is the use of emotive phraseology and powerful literary quotes [Nordlicht, 1982, Earnshaw-Smith, 1982]. Whilst this increases the "popular" appeal of such articles it does not further our understanding of the impact of the illness on the family.

The final perspective to be considered in this section is that of family systems theory. This approach sits astride the anecdotal and "scientific" approaches in the literature. Family systems theory is based on psychotherapeutic principles and

has been developed and validated over many years in child psychiatry [Barker, 1986]. In the field of cancer care, however, this perspective has been employed on a more ad hoc basis producing articles that sit more easily in the area of anecdotal literature than with those of a more "scientific", research orientated nature. Various papers exist which describe the application of this approach to oncology but make no attempt to assess its efficacy or applicability to the area of cancer care.

Brenner [1985] for example, discusses its potential use in the domain of hospice care, whilst Johnson [1988] describes its application in the field of oncology generally. These papers are much less emotionally laden than papers described previously in this section, but fail to produce validation of the use of this approach in these settings.

"Scientific" or empirical literature

The studies examining the psychosocial impact of cancer on the family have broadly looked at three areas: communication, terminal illness and general psychological effects at unspecified time points during the illness.

Communication

Krant and Johnston [1977-78] studied the patterns of communication in the families of 75 cancer patients at approximately two years following the diagnosis. The

researchers interviewed a range of different family members using an unstandardised, semi-structured interview. Krant and Johnston found that 46 per cent of the "first order relatives" (spouses, children, siblings) did not have a communication link to the patients' physician and that if a link was not established at diagnosis then this situation tended to remain unchanged. It was also found that communication and information between the family members was often discordant and guarded and that this led to the perception amongst them that the patient was withdrawing. More than half of the family members felt uncomfortable visiting the patient in hospital and experienced feelings of helplessness, in particular many felt that they did not know what to say.

Early studies such as this proved to very influential in changing hospital practice and emphasising communication with the whole family. They were viewed as useful descriptions which prompted similar projects to be undertaken in many cancer centres.

Hinton [1980] assessed the awareness of dying and the communication pattern between 80 married couples, where the patient was suffering from a fatal neoplastic disease. Sixty-six per cent of the patients recognised that they might or would soon die while 26 per cent spoke only of improvement, the remainder (8 per cent) were non-committal. Of the patients who recognised that they were dying, 69 per cent had spoken to their spouse about this issue. Hinton observed that

all of the patients who were certain that they were dying had discussed it with their spouse.

A surprising finding in this study was that anxiety level had no consistent effect in preventing communication between partners. Hinton emphasises this finding as the ethos in hospitals at the time was that troubled or anxious patients were believed to have poor communication with family, friends and staff.

These studies, although displaying methodological problems in terms of lacking comparison groups, using unstandardised assessment tools and including heterogeneous groups of cancer patients, laid the foundation for numerous studies in the area of communication between family members. Stedeford [1981], Fobair et al. [1986] and Hughes [1987] have all examined communication and the effect of the disease on communication between family members the results demonstrate the shortcomings in the health care system as well as suggesting ways in which improvements in communication styles and patterns can bring families closer together.

Terminal illness

The literature on the terminal phases of cancer is vast, although very variable in its quality. In the writings of Kubler-Ross [1969], Parkes [1972], Benoliel [1978], Kalish [1979], Mortocchio [1982] and Raphael [1984] the experiences

of dying patients and their families have been discussed from a variety of different perspectives.

In fact most of the research that has been conducted concerning the family's response to cancer, focuses on the terminal phase of the illness.

This literature addresses three principal areas: communication about death which has already been dealt with, the provision of care and support for the family and dealing with feelings of loss and separation.

Providing care and support for the family of the cancer patient

Family members often assume the primary caretaking role for the dying person, particularly in the community. Numerous studies have described this situation. Rose [1976] interviewed 26 families who were caring for a terminally ill family member. Not surprisingly it was found that these carers were the people most likely to help the patient with physical care and emotional support. Only one of the 26 families received assistance from a visiting nurse. This finding surprisingly was replicated by Parsons [1977] who reported that few people other than family members were involved in meeting the needs of the dying person.

The demands of caring for a terminally ill patient on their carer has been investigated by a number of researchers [Rose, 1976; Googe and Varrichio, 1981]. Family members in these studies reported decreased sleep due to factors such as worry, concern and having to provide physical care during the night. Vachon et al. [1977] found that family members developed their own health problems as they tried to cope with the stressful burden of care. Vachon et al. [1977] also found that the carers of terminal cancer patients often developed psychological problems such as anxiety and depression in response to feelings of impotence and helplessness as they watched their husbands die.

In this latter study the widows of 73 cancer patients were compared with the widows of 51 patients with chronic cardiovascular disease. The widows of the cancer patients thought that there was little they could do to help their husbands whereas the widows of the cardiac patients felt that they had an essential practical role in providing aid to their husbands. This latter group focussed particularly on encouraging their husbands to make lifestyle changes (diet and exercise) that they felt would be beneficial to their husbands' health. In addition, many of the cancer widows reported that their social support network had decreased as people had found the pattern of constant visiting too stressful to maintain.

Knowledge and information regarding care has been found to be important. Rose [1976] found that the majority of families interviewed, said that they needed more information about providing care in areas that required expertise and judgement on their part, such as pain control. Other studies have found that information is important for relatives in other aspects of physical care such as lifting, ambulation, wound dressings, and comfort measures as well as how to cope with the family changes that occur during the patients' illness [Edstrom and Miller, 1981; Googe and Varricchio, 1981; Grobe et al., 1981]. Problems experienced by the patient such as physical symptoms, anxiety and depression and the inability to communicate have been shown to be a major preoccupation for the spouse. As these symptoms worsen in the terminal phases of the illness the physical and psychological health of the spouse also deteriorates [Howell, 1986]. The concerns of the spouses, in this latter study, concerning changes in future lifestyle were found to be particularly potent in the development and maintenance of anxiety.

Wright and Dyck [1984] investigated the concerns of 45 adult family members at different stages during the illness "process". The four concerns most frequently identified were; problems created by the disease, fear of the future, waiting for results of tests and difficulties with obtaining information. Distress concerning symptoms increased with each progressive stage of the illness from 20 per cent at diagnosis to 53 per cent at the terminal stage. Fear of the future and waiting for results of tests were more acute at diagnosis and were cited

less frequently as the disease progressed, difficulty in obtaining information, however, remained a problem at all stages of the disease (diagnosis, recurrence, terminal stage).

When asked to specify the importance of certain needs six were regarded as important at all stages of the illness. These included: 1. the need to be kept informed of the patients' condition, 2. the need to be assured that the patient is comfortable, 3. the need to be informed of any changes, 4. the need to be with the patient as much as possible, 5. the need to communicate with the patient, 6. the need for acceptance, support, and comfort from nursing staff.

Since families provide a large part of the physical and emotional care of the patient, it is perhaps not surprising that they ascribe a high priority to symptom control, patient comfort and information regarding this aspect of care. If the patient develops symptoms the family will be the first to be aware of them and they will feel it their duty to act in order to alleviate the patients' suffering through direct or indirect action.

In view of the range, severity and distressing nature of the symptoms of the disease, it is not surprising that, if given the choice, carers would prefer that the patient died in hospital. Krant and Johnston [1977-78] in their study of communication in late stage cancer found that 20 per cent of the families interviewed preferred that the patient die at home, 16 per cent were uncertain and 55 per cent preferred the hospital

with an additional 9 per cent choosing hospital if the patient had pain (the study did not ask about the perceptions of hospice care in symptom relief). The symptoms experienced by the patient are important in dictating these responses, a study by Putnam et al. [1980], found that 50 per cent of family members would prefer the patient died at home providing symptoms such as pain were well controlled. The main factor being that hospital was felt to be better able to provide expert care and comfort.

Dealing with feelings of separation and loss

The final aspect of terminal illness to be dealt with is the feelings of separation and loss that co-exist with the provision of care for the patient.

The realisation in family members that they are losing their most important significant other is a time of anxiety, fear and confusion [Thomas, 1978]. A sense of helplessness often pervades [Krant and Johnston, 1977-78] and it is at this time that spouses have been found to perceive that health care professionals are less available to them and that they are being left to deal with the situations alone [Vachon et al., 1977].

In many of the descriptive studies undertaken during this time the widows report that the stress of the terminal phases of the illness was worse than the stress of bereavement [Vachon et al., 1977; Molter, 1979; Howell, 1986; Stetz, 1987].

The principal reason put forward for this has been the anticipation of loss and changes in lifestyle which people find extremely anxiety provoking [Howell, 1986; Stetz, 1987].

One of the major methodological problems in these papers is the use of unstandardised questionnaires often administered at unspecified times with families of heterogeneous groups of cancer patients. This complicates interpretation of the data and makes it impossible to develop a coherent picture of the experiences of cancer patients and their relatives.

"Psychometric" studies examining the impact of cancer on the family

The majority of the studies reviewed in this chapter have demonstrated that there are repercussions of an illness such as cancer on the family. The perspective that they have adopted is to emphasise the interrelatedness among family members and the mutual effect that they have on one another. From a family systems theory perspective, therefore, changes that occur in one part of the family system are accompanied by compensatory changes in another part of the system. In response to cancer, anxiety, depression or distress are not confined to the sick individual but reverberate throughout the family unit [Minuchin, 1974].

This view has prompted attempts to quantify the psychological impact on the family using reliable and valid psychometric tests and a rigorous research methodology.

An early study by Coursey et al. [1975] assessed 187 patients with various cancer types before the initiation of treatment (either chemotherapy or radiation therapy). Both patient and accompanying family member completed the Spielberger State-Trait Anxiety Inventory on a single occasion.

The data demonstrated that female patients were significantly more anxious than male patients in terms of state anxiety but no difference was found in trait anxiety. Family members on the other hand, scored higher on both measures than the patient. Female family members showed a trend towards higher state levels of anxiety but not on trait levels.

This early study is wholly inadequate in its design using a single measure of psychological distress administered to a wide range of patients at different stages of their illness on a single occasion. The results, however, do indicate that family members may experience higher levels of distress than patients and these results prompted the initiation of a number of more refined studies.

Leiber et al. [1976] interviewed 15 female patients and their husbands and 21 male patients and their wives who were already receiving chemotherapy for a variety of different tumours. The patients and their spouse completed the Beck

depression inventory, the Affectional Needs and Behaviour Scale (this scale measures the respondents needs for physical contact and the way in which these needs are expressed) and the Current State of Health Questionnaire (this measures the degree of pain, discomfort, incapacitation and worry experienced by the patient during the previous two days).

The results demonstrated that as a group neither the patients nor their spouses were suffering from severe depression at the time of the study. Women patients were the only sub group whose scores on the Beck Depression Inventory approached the depressive range while the husbands were the least depressed of the four subgroups.

With regard to "affectional needs", patients and spouses of both sexes reported a decrease in the desire for sexual intercourse but the desire for non-sexual closeness increased following the diagnosis of the illness. Forty nine per cent of the sample reported an increased desire for physical closeness and only 5.6 per cent reported lessened desire for this. Not surprisingly, a trend for sexual desire to decrease as depression increased was found.

The correspondence between changes in desires and changes in actual affectional behaviour was greater for patients than for spouses and was greater for female patients than for male. Thus, women patients, although significantly more depressed than the other three sub-groups were most likely to have

their affectional needs met while their husbands were least likely to have their needs met.

This study although using a single "snapshot" approach in monitoring depression and affectional needs does raise some important issues. It indicates that the needs of patients' husbands are poorly met, perhaps because they are infrequently expressed. It also suggests that patients and their spouse may experience increased intramarital tension as a consequence of disparate needs and altered roles.

There are methodological difficulties with this study. The psychometric assessment is only performed on one occasion and the requirement for both husband and wife to participate may have eliminated from the sample those couples with problems in marital adjustment. This latter bias may explain why so few of the patients were depressed for example. Despite these difficulties in the study design the data makes an important contribution in describing a group of individuals who may be at risk of developing later psychological and marital difficulties.

Other studies followed looking at the levels of psychological distress in both the patient and their spouses and produced some contradictory findings.

Plumb and Holland [1977] assessed depressive symptoms using the Beck Depression Inventory in 66 cancer patients with various types of cancer and their next of kin. All the

patients were undergoing chemotherapy treatment for their disease. Unfortunately, it was not possible in this study to control for the length of time since diagnosis of the illness or for the number of previous hospital admissions for treatment.

The results showed that 77 per cent of the cancer patients and 82 per cent of the next of kin scored in the "not depressed range". Nineteen per cent of patients and 18 per cent of their next of kin scored in the moderately depressed range and 4 per cent of patients and none of the next of kin scored in the severely depressed range using the cut off scores suggested by the authors of the Beck Depression Inventory. The authors in this study conclude that, "Based on their own reports on a standard measure of depression, hospitalised patients with advanced cancer were not significantly more depressed than their presumably healthy next of kin"(p272). The depressive symptomatology that did exist was more prevalent in the younger patients than the older and the severity of these symptoms did not systematically increase with nearness to death in 57 of the patients who died during the study.

Interestingly, this early study found that overall the self esteem of the cancer patient and their next of kin was relatively intact so that although the patient may loathe his or her situation they do not loathe themselves. This, the authors postulate, is the reason why very few of the patients in the study or their next of kin reported even considering suicide as a viable option for themselves.

Wellisch et al. [1978] investigated the reactions of 31 men to their wives' mastectomies using a variety of psychological tests: the Locke-Wallace Marital Adjustment Test, the Rotter Locus of Control Scale and the Eysenck Personality Inventory.

The results showed that psychosomatic and psychological reactions after the womens' surgery were frequent among the men and tended to be expressed from the time of the procedure until the woman was discharged from hospital. Sleep disorders and the presence of nightmares were reported in 40 per cent of the sample. Twenty seven per cent reported a loss of appetite and 6.7 percent reported an increase in their appetite. Forty three per cent of the men indicated that their ability to work was temporarily adversely affected by the experience, principally because of their inability to concentrate. In general, the men indicated that sexuality and sexual intimacy were severely stressed and often negatively altered after the mastectomy. This effect on sexuality was also found to be prevalent in the wives who underwent the mastectomy [Jamison et al., 1978].

The authors conclude that, "the results of this study showed that a sizeable proportion of this sample of 31 men either coped well with mastectomy in their spouses or denied psychosocial stresses. It was also evident that a smaller subgroup of this sample was distressed, remains distressed and reported a downward spiralling of the quality of their relationship"(p545).

One of the methodological problems with this study was the use of a single assessment. As a result the study is unable to indicate if the stressed sexual relationships may have recovered over time. The small sample size also makes multivariate analysis difficult to undertake as dividing the groups up by age, attitude or personality type, for example, would result in extremely small sub groups. The final problem in this experimental design is the lack of any standardised measure of mood, this should be an essential feature in any study designed to examine the psychological impact of cancer and its treatment.

Goldberg et al. [1984] in attempting to overcome some of the methodological difficulties inherent in previous studies selected patients with a single type of cancer and their spouses, used a selection of well validated and reliable psychological tests and obtained a measure of physical health status.

Goldberg et al. selected patients with newly diagnosed lung cancer and their spouses and assessed them within six weeks of their diagnosis and at two monthly intervals thereafter for a period of four months. The number of patients for which complete data was available was 21 patients and 18 spouses all of whom completed the test battery on three occasions over the six month period.

The psychological tests used included the Profile of Mood States, The Psychosocial Adjustment to Illness Scale and the

Karnofsky Performance Index. This battery assessed six different mood states, adjustment to illness in a number of different areas of life and physical health status.

The study, therefore attempted to investigate the relative contributions of physical health and social interests and involvement, to depression in patients with lung cancer and their spouses over a period of six months following diagnosis. The results demonstrated that the level of depression as measured by the Profile of Mood States decreased in patients and their spouses from the first assessment to the second and third. This suggests that diagnosis produces an acute increase in depressive symptoms which then subside over the four to six months following this.

No consistent relationship was found to exist between physical health, as assessed by the Karnofsky Scale and depression, or between depression and social interests and involvement in this period. At the final assessment conducted at six months post diagnosis, however, physical health status accounted for one half of the variance in patients' depression scores. This demonstrates that physical status was an important determinant of depression in the patients at that time whereas social interests and involvement continued to play no apparent role in the patients depression.

Factors contributing to depression in the spouses, however, were the reverse of this. High levels of depression were consistently associated with low levels of social interest and

involvement throughout the six month evaluation period but showed inconsistent associations with the patients physical health during that time.

These results are important in that they demonstrate that social involvement for the spouse, (in this study predominantly women), may be of special importance in contributing to depression. The study used reliable and valid assessment scales and examined both patients and their spouses. Unfortunately the period of the study ceased following administration of treatment, thus leaving a large part of the illness and future treatment "process" unaccounted for. The design of the study does, however, demonstrate the value of a longitudinal assessment of both the patient and their partner.

Gotay [1984] attempted to assess coping mechanisms and the resolution of problems at different points in the illness process in patients and their partners. She used a group of patients with "early stage" cervical cancer and their partners as well as a group of patients with "advanced stage" breast or gynaecological cancer and their partners.

Unfortunately the data for this study was collected using an unstandardised questionnaire designed by Gotay herself and no measures of mood or symptomatology were used. The study, therefore, is difficult to interpret but does view the illness as consisting of a "process" rather than a single point in time.

The results demonstrate that the spouses were more likely than the patients to dwell on the possibility of the patient dying and were more disturbed by this possibility than the patients. In fact, the most common concern reported by patients and their partners was their fear of the disease which was ranked as the principal response in both the early and advanced stages. The content of the fear was concerned with potential progression and recurrence of the tumour. The coping strategies employed to deal with these fears were consistent among the family. Both patients and their spouses used "action taking" as a common coping strategy with "information seeking" being the most commonly reported behaviour particularly in the early stages of the disease. The patients and spouses in the advanced stage group also found religious faith to be important as an effective coping strategy in relieving stress.

This study was extended by Gotay [1985] to examine attributions patients and their spouses made for the cause of the disease and its effect on their level of adjustment. In this study an unstandardised questionnaire was used but also some standardised measures of mood (Bradburn Affect Balance Scale) and social adjustment (Weissman's Social Adjustment - self report scale) were employed. Gotay utilised the same groups of patients as previously and interviewed them at two stages of the disease (early and advanced).

The results indicated that the majority of individuals cited chance as the cause of their cancer. This belief was not found to affect social adjustment negatively. In fact, the adjustment scores were not significantly different from the general population. Patients and the spouses in both groups were more stressed than the general population but were not as disturbed as a group of individuals receiving psychotherapy "for stress reactions". The attribution of causation did not affect mood negatively and Gotay concludes "it is suggested that not making strong causal attributions may be adaptive for cancer patients and their families"(p825).

Cassileth et al. [1985], recognising many of the shortcomings of studies in this area adopted a more rigorous research design than previous researchers. This study explored anxiety, mood disturbance and global mental health in a representative sample of cancer patients and their matched relatives.

The study assessed 201 mixed cancer patient-relative pairs at different point during the illness/ treatment "process", during active first line treatment, whilst patients were on follow-up observation and when they were receiving palliative therapy. The test battery used to assess each patient-relative pair consisted of the Spielberger State Anxiety Scale, The Profile of Mood States and The Mental Health Index.

The psychological status of patients and their relatives were closely correlated in terms of anxiety, mood disturbance and global mental health. This similarity was found to persist

between patient and relative across diagnostic group. As a group, patients displayed greater mood disturbance than their matched relatives. Treatment status (active, follow-up, palliative) was found to be significantly associated with psychological response in both patients and relatives. Psychological state was found to deteriorate according to the treatment status of the patient. Those receiving palliative care displayed the highest anxiety levels, the most severe disturbance in mood and the poorest overall mental health. This trend was observed for relatives and patients alike. Psychological well-being decreased when patients were receiving active treatment as opposed to follow-up care and decreased further when patients were receiving palliative therapy.

The explanation of this data by Cassileth et al. is that "palliation therapy, which is geared to attain comfort rather than cure or remission, coincides with nearness to death. This phase of treatment and of life offers minimal if any hope for recovery and, not surprisingly, is associated with significant degrees of anxiety, mood disturbance and poor mental health"(p75). The authors put forward the view that "patients who are not in an active phase of therapy but who are under follow-up medical care display, as do their relatives comparatively good psychological status. These patients and relatives are freed from the disruption and stress associated with cancer therapy itself, and generally have reason to believe that remission or cure has been obtained. Under circumstances of active treatment, however, patients and their

relatives have yet to attain that security, and are faced also with fears, inconvenience, treatment related toxicity and massive uncertainty"(p75). Thus the emotional status of this group reflects their situation and they show greater emotional distress than those people under follow-up care but less distress than those receiving palliative treatment.

The correlation between patients and their relatives demonstrates an interaction of family members in terms of psychological state. Undoubtedly relatives provide a psychosocial environment to which the patient reacts and, conversely, patients similarly influence the level of distress or adaptability exhibited by the relatives. Social support is not dealt with in this particular study but it may have a role in mediating distress particularly in view of the study reported by Goldberg et al. [1984] (discussed earlier in this chapter) which demonstrated the importance of social involvement for the relatives of lung cancer patients.

Cassileth et al. [1985a] repeated this study with a group of 374 patients with mixed cancer types and 378 of their relatives. The results demonstrated a robust effect in that palliative treatment as opposed to active or follow-up care was associated with a greater mood disturbance in both patients and their matched relatives. A poor performance status was also associated with a greater mood disturbance in the patient and their partner.

Baider et al. [1986] examined the impact of family environment on psychological distress in two groups of women with breast cancer and their husbands. Twenty five women underwent a lumpectomy and 26 underwent a mastectomy. Patients and their husbands were interviewed at about two years following the surgical procedure using the Spielberger State-Trait Anxiety Inventory, The Beck Depression Rating Scale, The Psychosocial Adjustment to Illness Scale and the Moos Family Environment Scale.

The two groups of husbands showed identical levels of adjustment which was not significantly different from the general population. Similarly, no differences were found between the two groups in terms of depression. In terms of anxiety, however, the post-lumpectomy husbands were found to score significantly higher that the post mastectomy group. And in terms of the family environment (cohesion, expressiveness, conflict etc.) scores of both groups were within the normal range for both groups of husbands but women in the post mastectomy group described significantly more organisation, cohesion, and less conflict than those in the post lumpectomy group, thus a more supportive family environment.

A comparison between the patients and their husbands also demonstrated that there were no significant differences between them on any of the measures.

This study used a comprehensive battery of psychometric assessment tools to monitor the psychosocial impact of the two operative procedures. Unfortunately the study uses a single assessment of psychological state and family relationships which limits the applicability of the findings. The single assessment point however does not enable the influence of time and stage of disease on adjustment and family environment to be assessed. The results suggest that the concept of "family environment" does not correlate significantly with psychological distress in this study at the point of assessment but this may effect may change as time from surgery increases, for example.

The concept of "social support" used in this study also warrants further consideration. The Family Environment Scale monitors the perception of family members of certain aspects of family function such as independence, conflict, achievement, religious activity and intellectual/ cultural activity. In using this type of measure to investigate social support a careful definition of the term based on a theoretical perspective is required and an appropriate tool selected. Multiple administrations are then necessary to monitor any fluctuations in levels of support throughout the illness and to assess its relationship to adjustment and psychological state.

The concepts of social activity, social interaction and social support have increasingly been regarded as useful in the amelioration of psychological distress. Evaluation of these concepts has been haphazard and unsystematic. Studies have

on occasion made the assumption that to increase the social interaction of family members would be beneficial even though evidence on this issue is equivocal, as will be discussed in the next chapter.

A study by Haggmark et al. [1987] encouraged relatives to increase their level of participation in the care of the patient. This would necessarily increase contact with a greater range of health care professionals as well as other patients' relatives in the same position. The relatives in this study reported an increase in social activities with family and friends as a result, but the study failed to include any measures of mood in its design so that the value of increased social interaction cannot be properly assessed. Such conceptual leaps in research design are not uncommon but in complex multifaceted concepts such as social support they can distort and confuse important questions and lead to confusion in interpreting the results of other research studies.

Goldberg et al. [1984] found that the distress in the family members of patients with lung cancer reduced over time. Cassileth et al. [1985], however, reported that if during the passage of time the patients treatment status changed i.e. the patient embarked on a different type of treatment or was given palliative therapy, then distress increased. Goldberg et al. [1984] also found that social interest and involvement were important in reducing depression in the patients spouse.

Ell et al. [1988] in an attempt to elucidate further the effects of time and social support examined 143 pairs of patients and their "significant others" at 3-6 months following initial diagnosis of breast, colorectal or lung cancer and again 6 months later. The measures used included the role limitation scale, the interview schedule for social interaction, the personal control inventory and the mental health inventory as well as measures of physical status and symptomatology. This battery assessed the availability and adequacy of social support, effects on lifestyle, the degree of feelings of personal mastery of the situation and level of mood disturbance.

The results of this study reveal some interesting differences from earlier data. A significant decline in mental health was observed in the patients and their carers over time and a group of carers who appeared to be psychologically vulnerable were clearly identifiable. They were consistently distressed over time and experienced no relief from this as time progressed.

Poorer psychological functioning among carers was associated with patients having more physical symptoms at initial diagnosis. It was noteworthy, however, that declining mental health status in the carer was not related to an increase in the patients role limitation or physical symptomatology over time. The early mental health status of patient and carer was found to be a strong predictor of subsequent psychological state. In contrast to earlier studies [Cassileth et al., 1985], the psychological status of patient and carer were not significantly

correlated either in those who were functioning poorly from the outset or in those who showed change over time.

The principal significant effect in this study was a strong association between declining mental health and declining social integration. At the same time, carers whose mental health improved over time experienced a significant increase in perceived adequacy of support and in social integration. This data leads Ell et al. to conclude," taken together these results suggest that individual personal and social resources rather than patient's physical condition, are primary factors in declining mental health status among significant others"(p436).

This data demonstrates that the relationship between psychological state, physical state and social support is far from clear and requires further study. The paper by Ell and her colleagues does however contain certain methodological problems. The study population contains three diagnostic groups all of which have very different prognoses in terms of survival time. This fact complicates the interpretation of the data as prognosis and site of disease are factors known to affect psychological adjustment [Weisman and Worden 1976-77; Cassileth et al., 1985].

A second problem in the design of the study is that the assessment points do not allow the researchers to control for treatment status effects which have been shown to be

important in determining psychological state [Cassileth et al., 1985].

Finally, no attempt was made to control for the type of treatment that the patients received. With the three diagnostic groups used in this study the treatment modalities of surgery, chemotherapy, radiotherapy and indeed no treatment may have been used. The psychological impact of treatment has been discussed earlier and is an important variable in research in this field.

One particular phase of the illness "process" that has received scant attention is the period following discharge from hospital when the patient has received treatment and thereafter, is regularly monitored at follow-up outpatient visits. Oberst and James [1985] undertook a preliminary study of needs in patients and their spouses following discharge home after surgery for cancer. This reported anger and frustration in spouses concerning a perceived lack of support from all sources including health care professionals.

This study was later extended and a more rigorous research design utilised [Oberst and Scott, 1988]. The subjects consisted of 40 patients undergoing surgery for cancer of the bowel or urinary system, and their spouses. Half of the group had a permanent ostomy as a result of surgery and the remainder did not. The subjects were assessed using the Spielberger State Anxiety Index, the Brief Symptom Index and the Vulnerability index at 10, 30, 60, 90 and 180 days following discharge from

hospital. The intensity of psychological distress experienced by patients and their spouses was remarkably similar and correlated, although the temporal pattern of occurrence was significantly different. Prior to discharge, spouse anxiety was significantly higher than that of the patients due to the anticipated worries and concerns about their own ability to cope. Spouses were least distressed after ten days at home, but thereafter experienced a significant rise in distress culminating in observable clinical depression at 90 and 180 days. Peak distress for the patients, however, occurred 10 days after discharge as a function of physical symptoms that were unexpected or more severe than anticipated.

The authors reported that the distress which spouses began to experience two months following discharge "appeared to be a response to the patients' continued egocentricity regarding symptoms and a perceived lack of support and understanding of their own plight."

This paper demonstrated a combined effect of physical symptoms and lack of support which contrasts with previous data. The period of study is highly specific and does not investigate patients at relapse or during palliative treatment. It does, however, provide valuable longitudinal information during the post discharge period. One major methodological shortcoming of the study is the way in which social support was assessed. This took the form of a series of semi-structured questions relating to problems and concerns and this relied on the respondents volunteering the fact that they lacked a social

support network. The study on the other hand does overcome many of the shortcomings of previous attempts using a single disease and valid and reliable assessment scales.

Finally Baider et al. [1989] have reported the adjustment of 39 couples in which one partner had undergone surgery for colon cancer in the previous three years. These researchers were particularly interested in the gender of the patient and spouse as this was felt to be a variable neglected by previous studies. Patients completed the Psychosocial Adjustment to Illness Scale and the Brief Symptom Inventory on a single occasion.

Male patients were found to adjust better than female patients while the opposite was true of spouses i.e. the adjustment of husbands was much worse than that of wives. Overall the adjustment of the group of patients and their spouses was strongly correlated.

This latter paper is a preliminary communication of research findings and presents no data on the effects of symptom severity and social support. It does, however, raise the question of the effects of gender in investigating the psychosocial impact of cancer on the family.

Other factors which have been examined in relation to impact of cancer on the family are concerned with support from health care professionals and offering patients a choice of treatment.

Maguire [1981] interviewed 52 men whose wives had undergone simple mastectomy and radiotherapy and 40 men whose wives had been treated for benign breast disease. Thirteen per cent of the husbands in the mastectomy group were rated by a psychiatrist as having moderate anxiety and 4 per cent as having severe anxiety when assessed three months after the operation, and a further 49 per cent experienced mild anxiety. In the husbands of women with benign breast disease 2 per cent had mild anxiety and 5 per cent moderate anxiety. When assessed one year after the surgery symptoms of anxiety were evident in 36 per cent of the spouses of mastectomy patients and 13 per cent of the "benign" group. However, these were mild in severity in all but 6 per cent of "mastectomy" spouses and 3 per cent of the 'benign' group.

Depression was found to be much less of a problem, and in those spouses who did manifest depressive symptomatology it tended to be rated as "mild". At the one year assessment following surgery there was no significant difference between the levels of depression in the "mastectomy" and "benign" groups.

Only seven per cent of the husbands who were distressed and anxious had been able to discuss their fears and worries with the medical or nursing staff and 82 per cent considered that they had not been allowed to play sufficient part in the decision making about mastectomy. Seventy two per cent believed that they should have been allowed to discuss the impending surgery more fully with their wives and the

medical staff. This lack of opportunity to discuss fears, worries and treatment with an "expert" were found to increase levels of anxiety and distress in the spouses.

Morris and Royle [1987, 1988] studied two groups of women with early breast cancer and their husbands. The first group were offered a choice of surgery (simple mastectomy or wide excision plus radiotherapy) and the second group were not. The levels of anxiety and depression were assessed using the Hospital Anxiety and Depression scale, before surgery and then post operatively at 2-3 monthly intervals for a total of 10-12 months.

The results demonstrated that a significantly higher percentage of the patients not offered a choice of surgery experienced clinical levels of distress (anxiety and depression), pre-operatively and up to 2 months post operatively compared with patients offered a choice; the results also proved to be identical for the husbands of these patients. At six months the differences between the two groups were not significant although the trend remained towards elevated levels of anxiety and depression in those patients who had not been offered a choice of treatment.

The main emphasis of the research in this area has been to assess the relative contributions of physical symptoms and social support to psychological distress resulting from the diagnosis and treatment of cancer on the family. The results

to date, unfortunately leave the picture far from clear and further research of a more rigorous nature is required.

The impact of cancer on family life

Studies have often used a methodology combining a "psychometric" approach with questionnaires examining a more global impact on family life. These studies examine aspects such as the effect of work, sexual relationships and marital relationships and will be reviewed briefly here as they add an important dimension to this field.

Work

Much of the research concerned with the impact of the disease on employment has been conducted in the United States. In the economic environment of the U.S.A. a significant proportion of former cancer patients are denied work or discriminated against because of the disease [Feldman, 1978], although other studies have shown that these prejudices are not universal and may vary between companies [Wheately et al., 1974]. Fobair et al. [1986] found that 42 per cent of their sample of cancer patients reported difficulties at work often due to lassitude following treatment or problems with insurance.

Maguire [1981], examining the repercussions of mastectomy on the family, found that of 43 spouses regularly employed before the surgery 26 per cent were experiencing difficulties

in their work at three months after the operation and that 25 per cent of the 43 spouses were still experiencing work difficulties a year later. They found it more difficult to concentrate, make decisions and generally enjoy their work.

The impact of cancer on employment, therefore, affects the spouse as well as the patient. The patient may experience difficulties with mortgages and insurance for work (USA data), whereas the spouse may experience difficulties in terms of their psychological state and attitude.

Social and leisure activities

Maguire [1981] has shown that effects on body image may cause the patient to withdraw from former social and leisure activities. The spouse also may be adversely affected. Maguire [1981] found that 16 per cent of husbands felt that their social life had diminished since their wives' mastectomy three months earlier. They attributed this to their wives reluctance to go out and their unwillingness to pressure them to do so. Ten per cent of the spouses claimed that relationships with friends outside of their immediate family had deteriorated seriously. Seventeen per cent of this group of husbands when assessed one year after the surgery were found to have experienced a restriction of their social and leisure activities and 12 per cent suffered obvious deterioration in their relationships with people outside of the family.

Families have also reported that their social and leisure activities decline because friends treat them differently which results in feelings of alienation and isolation [Peters and Golden, 1982].

Marital and Sexual Relationships

Investigators have tried to determine what effects cancer has on the relationship between spouses. The results are mixed. Grandstaff [1976], Leiber et al. [1976], Spiegel et al. [1983] found that some marriages improve following cancer and that there is an increased closeness between the partners. Leiber et al. [1976] in their study of 38 patients receiving chemotherapy for advanced cancer noted that even in this group, the stresses of illness did not produce emotional alienation or withdrawal of affection between the partners.

While cancer does not appear to alter marital relationships appreciably, Checkryn [1984] found that the strain in marital relations occurs at certain times, for example at the time of recurrence. Fobair et al. [1986] on the other hand, interviewing patients with Hodgkin's disease nine years after treatment found that 29 out of 69 patients had divorced since their initial diagnosis and that of these 49 per cent attributed their divorce to their disease.

Other studies have found that those couples who had an unstable relationship before their illness are more adversely affected and that the higher separation rates in certain studies

reflect this [Bard and Sutherland, 1955; Grandstaff, 1976; Ray, 1977; Jamison et al., 1978].

Investigators looking at the impact of breast cancer and its treatment have been particularly interested in the effects on sexual relationships. Wellisch et al. [1978] reported that sexuality and intimacy were altered following mastectomy. Thirty six per cent of the husbands in this study reported a negative effect on the sexual relationship. However, the husbands who reported more sexual problems following mastectomy also reported lower sexual satisfaction prior to the surgery.

Maguire [1981] found that 21 per cent of the 38 husbands whose wives underwent a mastectomy and who had a good sexual relationship before surgery reported a moderate to marked deterioration three months after surgery. At a follow-up interview one year later 29 per cent of the husbands reported moderate or severe sexual difficulties. The husbands attributed these to their wives loss of interest and their own unwillingness to pursue the issue.

The effect of the disease and its treatment on sexual activity depends upon the disease site and the type of treatment. Many patients feel that their illness has made then sexually unattractive particularly if they have had operations such as colostomy [Devlin et al., 1971; Thomas et al., 1987] orchidectomy [Rieker et al., 1985] or limb amputation [Sugarbaker et al., 1982] but these effects are not confined

solely to patients who have undergone mutilating surgery. For example, Fobair et al. [1986] found that 36 per cent of the sample reported a decrease in sexual activity and of this group 56 per cent felt that it was related to the illness and its treatment. Younger patients reported less change than older patients and patients with longer follow up times were more likely to have recovered normal sexual frequency. Treatment was found, in this study to have some effect, patients treated with radiation alone were less likely to report a decrease in sexual frequency than patients treated with a combination of radiotherapy and chemotherapy. It was also found that loss of energy and symptoms of depression were correlated significantly with decrease in sexual frequency.

The effects on family life are, therefore, varied and complex and it is essential that future studies conducted in this field take into account the potential impact of the disease and its treatment on the family's psychosocial functioning.

Summary and methodological critique

The literature concerned with the psychosocial impact of cancer and its treatment of the family is relatively sparse and much of it uses flawed research methodologies. Psychological distress has been shown to exist in the patients' spouse but the relationship between the two members is unclear at present. Similarly, the changes in distress during the course of the disease have still to be fully elucidated as well as the role of factors such as physical health status and social support in

contributing to this. The available literature also indicates that cancer has an impact on various aspects of the lives of families, such as employment, marital and sexual relationships and that these effects vary during the course of the illness.

There are a number of methodological problems with the research conducted to date in this area:

1. Much of it is based on anecdotal or unstructured interviews making interpretation and comparison of studies difficult. Standardised assessment tools are required that are valid and reliable and that are appropriate for use in the field of oncology.

2. Assessment of psychosocial functioning is often limited to mood or return to work. This type of assessment needs to be broader in content in order to investigate the impact of a wide range of factors.

3. Many studies use a group of patients and their relatives suffering from a variety of cancer types. Thus, it is not possible to examine the effects of specific treatments, specific sites of disease and stages of disease accurately. It is important in designing studies in this area to use a single disease group so that these variables can be controlled as accurately as possible and their contribution assessed.

4. Single assessments of patients and their relatives are inadequate but are often used in research studies. Repeated examinations of the subjects are required in order to monitor

changes in the psychosocial status during the course of the disease and its treatment.

5. Studies have tended to assess either, the spouse or the patient. This means that the relationship between them in terms of psychological state cannot be examined. Both patient and spouse should be assessed through the illness in order to obtain a coherent picture of interrelationship between them over time.

It is perhaps a salutary note that many of these methodological problems were described over a decade ago by Plumb and Holland [1977]. The conclusion of this paper is as valid now as it was then as many researchers in this field have failed to heed their recommendation:

> "We are aware that any fully adequate study.....in cancer must be longitudinal, with repeated ratings of mood throughout the illness course"(p274).

Not to be deterred the authors conclude in a later paper with a similar plea:

> "Further studies of the psychological functioning of cancer patients are needs that are longitudinal and that assess patients' coping skills as well as their psychologic impairment."[Plumb and Holland, 1981](p253)

Chapter Five

SOCIAL SUPPORT AND COPING WITH CANCER.

Coping with cancer can be facilitated by a number of factors and in order to understand the role of social support in this area it is necessary to understand the general concepts involved in coping with stress.

Coping with cancer

Coping with the stress of cancer can be explained using a model put forward by Lazarus and Folkman [1984]. This model is composed of three stages:

1. Primary appraisal - is there a threat?
2. Secondary appraisal - what can be done about it?
3. Coping - implementing strategies for coping.

This process of appraisal and coping can be viewed as a continuing series of reactions to the varying stresses which cancer imposes and the "process" will vary with the course of the illness. Greer [1985] has hypothesised that at the time of diagnosis the person needs to decide the degree of life threat that the disease brings with it. Initially, the diagnosis is seen as a "catastrophic threat tantamount to a death sentence".

As time progresses, however, and the patient is able to assimilate further information about the treatment and the

options available, a more optimistic appraisal of the situation may be made.

Appraisal of threat and the social interpretation of cancer

A number of different factors are important in helping the patient make an appraisal of the degree of threat that cancer presents them with and as a result play a part in the development of the coping response. Initially, patients evaluate the threat that the illness poses to their life (primary appraisal). This is then tempered by the patients' perceptions of their own ability to cope with the disease as well as the ability of their family and the medical team (secondary appraisal).

Indeed, other studies [Feifel et al., 1987; McCorkle et al., 1983; Kneier et al., 1984] have noted that patients reactions to life threatening illness is very different from patients facing severe, non-life threatening conditions or potentially life threatening conditions. The view of an illness or disease held by society is thought to be responsible for this difference. McCorkle et al. [1983] for example studied 56 patients with cancer and 65 patients who had suffered a myocardial infarction within the previous two months. Striking differences were found to exist between the two groups. The cancer patients perceived their plight as being much bleaker than that of the heart attack patients. They experienced more symptom distress, reported considerably more health and

existential concerns and suffered more mood disturbance than the heart attack group.

This data supports the view that cancer patients are able to discriminate the degree of life threat that they are exposed to, at least in a cognitive sense. They probably use information gleaned from the media and beliefs of the general population to make a judgement regarding the severity of the situation.

Indeed, cancer patients have been shown to adopt specific categories of mental adjustment to cancer [Greer et al., 1979]. Greer et al. studied 69 consecutive female patients with early breast cancer, from diagnosis until five years after initial surgery. They found that in terms of their cognitive style patients could be placed in one of the following groups:

1. Fighting spirit - the patient shows no apparent emotional distress, fully accepts the diagnosis of cancer, adopts an optimistic attitude, seeks information about the cancer and is determined to fight the disease. This group accounted for approximately 17 per cent of patients in the study.

2. Denial - the patient shows no apparent emotional distress but either rejects the diagnosis of cancer or evidence of the disease or denies/minimises its seriousness. Seventeen per cent of patients in the sample fell into this group.

3. Stoic acceptance - the patient shows initial emotional distress followed by an acknowledgement of the diagnosis and a determination to carry on a "normal" life, seeking no further information about their illness and ignoring its presence as far

as possible. Fifty six per cent of patients in the sample fell into this group.

4. Helplessness/hopelessness - the patient is obviously distressed and is engulfed by the knowledge of the disease, daily life is disrupted by a preoccupation with cancer and the fear of impending death. Ten per cent of patients in the sample fell into this group.

This study continued to look at the effect of coping style on survival. The data showed that there was a statistically significant association between patients initial psychological response to the diagnosis (as assessed three months after operation) and outcome at five years. A favourable outcome (i.e. being alive) was more frequent in patients whose responses had been categorised as showing denial or fighting spirit (75 per cent) than in patients who had shown either stoic acceptance or helpless/hopeless response (35 per cent). Pettingale et al. [1985] re-examined the status of this group of patients after ten years. He found that of those who had adopted denial or fighting spirit, 55 per cent were alive with no recurrence, compared with only 22 per cent of patients who showed stoic acceptance or helpless/hopelessness at diagnosis.

The tentative conclusion drawn from this data is that the coping style adopted by patient affects the outcome in terms of survival. The hypothesis for the mechanism of such a finding is that the effect is mediated through biological mechanisms, possibly neuroendocrine or immune pathways.

An alternative explanation could be that the psychological responses associated with unfavourable outcome were themselves the result of occult metastatic disease. This is a plausible hypothesis as occult metastases are notoriously difficult to detect using standard medical investigations [de Vita, 1985]. The number of patients in the study was relatively small and it would be erroneous to make sweeping generalisations from one patient group, those with breast cancer. Particularly as some malignant breast tumours have been shown to be hormone sensitive and there is a clear link between certain psychological factors and hormone release (de Vita, 1985), other types of cancer may not be so susceptible to these potential influences.

Some of these criticisms have been answered by a replication study carried out in a series of 117 newly diagnosed patients with malignant melanoma [Di Clemente and Temoshok, 1985]. They found that women showing stoic acceptance and men with high helpless/hopeless scores had a greater risk of disease progression. It was found in this study that these psychological predictors were independent of the two biological prognostic factors measure, namely tumour thickness and clinical stage of the disease.

Greer and his researchers at the Royal Marsden Hospital are continuing to study the concept that psychological coping strategies affect survival. To this end they have developed a scale, the mental adjustment to illness scale which is a self rating questionnaire measuring fighting spirit, fatalism

(formerly called stoic acceptance), helplessness/hopelessness, avoidance (formerly called denial) and a new category referred to as "anxious preoccupation". This scale is being used in a large prospective study to select patients who might benefit from a psychological intervention programme and in this way clarify the effect of coping style on survival [Watson et al., 1988].

Thus, the patient who views cancer as a challenge and feels that they may have some influence over the disease makes a better adjustment. Once patients have achieved this way of coping with stress, appropriate strategies can be implemented based on the coping style that predominates.

The way of coping adopted by patients is not fixed or mutually exclusive. One of the strengths of the Mental Adjustment to Cancer scale is that it enables a profile of the respondents coping style to be obtained rather than trying to force them neatly into a "pigeonhole". Research in this area suggests that the picture is complex and attempts to document a consistent fixed style or response to traumatic events have failed to do so. The measurement of personality traits, for example poorly predicts response to such events [Cohen and Lazarus, 1973; 1979]. In addition, an earlier study conducted by Morris et al. [1977] indicates that the patients exhibiting denial or "fighting spirit" characteristics originally, moved into the stoic category over the next two years. She found the category of "stoic acceptance" to be the most stable category over the two year study period: only three of the patients placed in this category

at three months were not so placed at two years, whereas patients with other types of response tended to change category. Similarly, the work of Weisman [1979] puts forward the view that "coping styles" and strategies may change over the course of the disease. More sophisticated theories of coping demonstrate that people are more variable than consistent in their coping patterns [Folkman and Lazarus, 1980].

Folkman and Lazarus [1980] analysed the ways in which 100 men and women coped with stressful life events over a period of one year. These researchers state that "coping is also a shifting process in which a person must at certain times, rely more heavily on one form of coping"(p221). The complexity of this concept is perhaps best exemplified by Moos and Tsu [1977] who postulate that in coping with physical illness a patient must deal with many sources of stress, including pain and incapacity, hospital environments and the demands imposed by the treatment procedures. At the same time, the patient must also try to preserve emotional balance, a satisfactory self image and good relationships with family and friends. These multiple tasks require an array of coping strategies, the complexity of which simply cannot be captured in a unidimensional measure.

Folkman and Lazarus found that the meaning of an event, the potential to change this event, coupled with certain psychological characteristics of the individual are the most important factors in shaping or changing the coping response. Coping and adjustment is clearly a complex area and is

influenced by a wide range of factors. It continues to be an area of fruitful research particularly in relation to an individual adaptation to severe life events such as cancer.

Locus of control

The concept of locus of control has been applied with increasing frequency to health and in particular to the area of coping and adjustment. People with internal expectancies of reinforcement ("internals") generally perceive that their outcomes are contingent on their own behaviour, whereas those with external expectancies ("externals") perceive a lack of contingency between their actions and subsequent reinforcement and believe that external sources such as chance, fate, others, are responsible for their outcomes [Lefcourt, 1976; Rotter, 1954,1966].

A review by Strickland [1978] demonstrates that patients with tuberculosis with internal expectancies were more knowledgeable about their disease (controlling for intelligence) than were those with external expectancies. Other research has shown that "internals" are more likely than "externals" to assume responsibility for their postoperative care [Johnson et al., 1971], to practice preventive dental care [Williams, 1972], to hold positive attitudes toward physical exercise [Sonstroem and Walker, 1973] and to report better health and have fewer illness episodes [Seeman and Seeman, 1983].

With respect to psychological well-being a more external orientation has been found to be directly related to mood disturbance [Kilpatrick, Dubin and Marcatte, 1974] depression [Calhoun et al., 1974], anxiety [Watson, 1967] and lowered goal expectations [Strassberg, 1973].

Research in this area has also extended into the field of oncology. Taylor et al. [1984] found that breast cancer patients who believed that they could exert control over their illness showed better short and long term adjustment than did patients who did not hold these beliefs. More recently Marks et al. [1986] studied a group of 137 patients with haematological malignancies. They found that the relationship between cancer patients perceptions of the severity of their illness and depression was markedly less for those who believed that they could personally control their health and for those who held positive expectations about the effect of complying with medical treatment. The researchers conclude that "beliefs and expectations about the role self plays in controlling one's health can indeed have functional value for someone with a serious illness"(p448).

The concept of locus of control is regarded as being stable over time in healthy individuals [Lau, 1982] but little is known about the stability of the concept in patients suffering from a serious illness such as cancer. It has been postulated that there may be a complex interaction between locus of control and information given about the illness, its treatment and prognosis [Marks et al., 1986]. For example, one could consider

the scenario where a patient with lung cancer who has strong beliefs in self control is told that he has an incurable condition that does not usually respond to treatment. The interaction in this case is potentially complex and is an area in which further research is required.

The role of information in adjustment to cancer

The last 25 years have seen a dramatic shift in the stated policies of physicians regarding the disclosure of information to cancer patients. A survey conducted in 1961, for example, found that 88 per cent of the physicians questioned had a policy of not disclosing the diagnosis of cancer to the patient [Oken, 1961]. In 1979, however, 98 per cent of those surveyed had a policy of telling the cancer patients their diagnosis [Novack et al., 1979; Veatch, 1980]. This clearly demonstrates a considerable change in physicians' stated policies over the past two decades.

Slevin [1987] feels that the public perceives doctors as being divided into two groups: "tellers" and "non-tellers" of bad news. The former, Slevin claims are stereotyped as believing that patients should be given all available information and the latter as believing that patients would be harmed by such information.

Slevin [1987] postulates that some doctors deliberately withhold information on the grounds that patients will ask questions if they want to know the answers and that too much

information will only be upsetting for the patient, maybe even causing the onset of depression.

Certainly reports in the literature have shown that patients are dissatisfied with the information given to them by their doctors [Freeman et al., 1971; Stiles et al., 1979; Tuckett and Williams, 1984; Fallowfield et al., 1986]. A large discrepancy exists between the stated policy of physicians with respect to giving information and the receiving or recalling of that information by the patient.

Information has been shown by a number of authors to be linked to a positive adjustment in cancer patients [Feldman, 1978; Weisman and Worden, 1980; Hogbin and Fallowfield, 1989]. Lazarus [1966] regards information seeking as the principal method of coping with threatening events. He also suggests that it is one of the early processes of adjustment and coping, in the appraisal and re-appraisal of a harmful or threatening situation. Both appraisal and reappraisal occur for the most part, through the interpretation of data and are not simple perceptions of harms, threats or resources for coping [Cohen and Lazarus, 1979; Folkman and Lazarus, 1980]. Therefore, information seeking may precede and/or co-exist with appraisal and reappraisal.

The information needs of patients are likely to vary throughout the illness process. Mages and Mendelsohn [1979] for example, found that the major issues in the "diagnostic phase" of the illness are the recognition of the disease and its

implications and that the major tasks are the appraisal of the discovery's significance and the initiation of appropriate treatment. Cassileth et al. [1980] found that cancer patients generally seek maximum information about the disease after the diagnosis, as a means of gaining control. The inference that the latter researchers make is that appraisal and information seeking are among the early attempts of coping with the diagnosis.

A number of other studies have looked at the nature and scope of information required by patients soon after diagnosis. The body of research broadly demonstrates four major categories of patient concerns:

1. Disease related concerns which includes information concerning diagnosis, tests assessing the nature and extent of disease, treatments and prognosis [Feldman, 1978; Greenleigh Associates, 1979; Mages and Mendelsohn, 1979].

2. Personal related concerns that include physical and psychological well being and information regarding current and future employment and appropriate plans and goals for the future [Jones, 1981; Weisman and Worden, 1980].

3. Family related concerns which include the need for information regarding the effects of the illness and its treatment on the spouse, children, parents and siblings [Feldman, 1978; Jones, 1981].

4. Social related concerns which includes the need for information regarding the effect of illness and treatment on leisure activities, socialising and sexual relationships [Greenleigh Associates, 1979].

There is very little information, however, regarding the changing importance of these informational needs through the course of the illness and there is also a dearth of research during the later stages of the disease.

The body of research demonstrates that information is very important in the early adjustment of the cancer patient. Information concerning the diagnosis, treatment and its side effects and prognosis, are necessary to help form an appraisal of the likely threat of the disease. This then helps the patient implement coping strategies and hopefully adjust to the situation.

The complex nature of the relationship between personality traits such as locus of control, information given by health care workers and the "popular" beliefs of society is not fully understood. Undoubtedly they all have a role to play in the development of adjustment and coping with a malignant disease.

Social support and cancer

The past decade has seen the integration of social support into the concept of coping. It is regarded as a multidimensional

construct by a number of authors [Pinneau, 1975; Caplan et al., 1978; Walker et al., 1977; Murawski et al., 1978] and contains within it elements essential to the development of coping strategies.

Numerous authors have developed taxonomies or lists of components of social support and drawing from these, it is possible to identify several distinct types. One involves the expression of positive affect which may include information that one is cared for, loved and esteemed [Cobb, 1976]. A second, involves encouraging the open expression of beliefs and feelings [Wortman and Dunkel-Schetter, 1979; Dunkel-Schetter, 1981]. A third, closely related aspect of support, involves expressing agreement with or acknowledging the appropriateness of a person's beliefs, interpretations or feelings [Walker et al., 1977; Kahn and Antonucci, 1980; House, 1981]. A fourth type is the offering of advice and/or information which can be from both formal and informal sources or the access to new and diverse information (this aspect, dealt with earlier in this chapter, has been shown to be essential in the development of effective coping strategies) [Caplan, 1974; Barrera, 1981; House, 1981]. A fifth type of support is the provision of material aid and tangible resources [Caplan, 1974; Kahn and Antonucci, 1980; House, 1981]. Finally, support may be conveyed by providing information that the person is part of a network or support system of mutual obligation or reciprocal help [Walker et al., 1977; Kahn and Antonucci, 1980; Barrera, 1981].

Researchers have maintained that despite the apparent overlap among these components, each should be considered as potentially important and that its impact on health and well being should be treated as an empirical question [House, 1981].

There are several reasons which it is desirable to assess distinct types of social support. Thoits [1982] for example, has reviewed evidence suggesting that not all types of support are equally effective in reducing distress. In the field of cancer care, emotional support has been identified as being most helpful to patients in reducing distress and giving reassurance [Moos and Tsu, 1977]. However, in terms of physical recovery following treatment, tangible support was found to be the most helpful over and above other types [Raphael, 1977].

In considering the role of social support for the cancer patient it is important to consider which types of support may be particularly important in helping them cope with the stresses imposed by the illness and, therefore, relevant to examine and measure.

Structural and Functional Aspects of Social Support

Precise definition is essential when considering social support. For example, a clear indication of structural versus functional aspects must be made. Structural measures indicate the range and interconnectedness of support. These measures are often regarded as objective indicators, to the extent that they assess

the presence or absence of fundamental social relationships and ties [Berkman, 1985]. The structural aspects of social support range from evidence of simply the presence of others [Cassel, 1974] to indices of social network [Berkman and Breslau, 1983]. They include factors such as marital status, membership of formal organisations, attendance in church and the number of people generally encountered, and the frequency of those encounters. They do not, however, give any indication of the quality of these interactions or their perceived value.

In contrast to the structural measures of social support, are the functional measures. These identify the qualities of social relationships and are generally operationalised as, the perceptions of the recipient; an approach derived from psychological (cognitive) and social psychological paradigms. The functions of social support that have been assessed have included very general measures such as the overall quality of social relationships [Blazer, 1982; House and Kahn, 1985] and social companionship [Wills, 1985]. The measures also include specific social support functions such as esteem, instrumental and information support [Wills, 1985] the intimacy of social relations [House et al., 1982] and the availability, quantity, timing and satisfaction with social support [Cohen and Syme, 1985].

Main Effect versus Buffering Hypothesis of Social Support

As well as defining the type of social support under examination, one must also consider the model of social support effect that is being used. Social support has been formulated in two principal ways with respect to health.

The first model proposes that social support has a beneficial effect on health per se; this model is termed the **"main effect"** model. This approach is based on the hypothesis that a generalised beneficial effect of social support should occur because large social networks provide people with regular positive experiences and a set of stable, socially rewarding roles within a "community". This type of support provides positive affect, a sense of stability in a milieu and a recognition of self worth and, therefore, promotes and maintains a state of overall well-being. Integration in this type of social network may also aid in the avoidance of negative experiences that may increase the probability of psychological or physical disorder. This perspective has received much support over the past decade [Levinger and Huesmann, 1980; Moos and Mitchell, 1982; Reis, 1984; Wills, 1985] and in its most extreme form the "main effect" model postulates that an increase in social support will result in an increase in well being irrespective of the existing level of support.

The second model of social support proposes that support is related to well being primarily for people under stress. This is

termed the **"buffering" model** because it posits that support "buffers" or protects against the potentially pathogenic influence of stressful events.

Social support may intervene between the stressful event and a stress reaction by attenuating or preventing a negative stress response. This may occur because of the perception that others may re-define the potential for harm posed by a situation and/or enhance one's perceived ability to cope with imposed demands, and hence prevent a particular situation from being appraised as highly stressful. Secondly, "adequate" support may intervene between the experience of stress and the onset of the pathological outcome by reducing the stress reaction or, by directly influencing physiological processes. Support may, therefore, alleviate the impact of stress appraisal by providing a solution to the problem or by reducing the perceived importance of the problem by "damping down" the psychoneuroendocrine system thereby rendering the individual less reactive to perceived stress and facilitating "healthy" behaviour [House, 1981]. It is this "buffering" hypothesis that is the central issue of this review and subsequent study.

Social support and adjustment

Adjustment has been viewed in a variety of different ways in the literature. Authors studying the effects of social support in the mental health field have considered psychological well-being as the appropriate outcome measure [Brown et al., 1975;

Holahan and Moos, 1981; Turner, 1981]. Others have considered the effect of social support on social functioning [Bloom et al., 1984; Bloom and Spiegel, 1984] or physical well-being [Berkman and Syme, 1979; House, 1981]. This review is principally concerned with the effects of social support on well-being.

Support, as described earlier is a multi-dimensional construct. In the field of adjustment to a stressful event, in this case a serious illness, one particular type of support has been found to be particularly important.

Emotional support, that is, the perceptions that one is cared for and loved or has a confidant or intimate friend has been related to lower levels of distress and depression [Gore, 1978; Holahan and Moos, 1981]. Numerous studies have linked the existence of emotional support provided by networks such as relatives and friends to improved levels of mental health [Brown et al., 1975; Holahan and Moos, 1981]. Turner [1981], for example, have shown that this type of support is related to improved adaptation to stressful circumstances resulting from diverse life crises such as assuming the mothering role, acquired hearing loss and functional psychoses and having a disabled child within the family [Dow, 1965].

Vachon [1984] demonstrated that social support was of benefit to women diagnosed and treated for breast cancer. Vachon [1984] compared women recently diagnosed with breast cancer with women who were recently widowed. The two

groups were comparable in terms of age and socio-economic status but differed in terms of urban-rural residence. They were assessed soon after the particular life event and again two years later. The outcome measure for distress was the Goldberg, General Health Questionnaire and social support was assessed using the subjects' perceptions of emotional support from family, friends and health professionals. The results demonstrated that a perceived lack of emotional support during the initial crisis was predictive of high levels of distress at the two year follow-up interview for both groups.

Funch and Mettlin [1982] examined 151 female breast cancer patients retrospectively. Subjects were interviewed regarding the extent to which three forms of support (social, financial and support from health care professionals) were related to psychological adjustment and physical recovery. The results demonstrated that social and professional support were significantly positively related to psychological adjustment whereas financial support was significantly positively related to physical recovery.

In this study the components of both social support and professional support included the extent to which subjects perceived they could talk to family, friends and health care professionals and the extent to which they could confide their fears ad worries without being rejected or uncomfortable. The results demonstrate that perceived social support in particular was related to increased levels of positive affect rather than to decreased levels of negative affect. This is an important

distinction which demonstrates a "health" promoting effect in psychological terms.

This finding echoes conclusions drawn from other studies in this field. Dunkel-Schetter [1981], for example, found that emotional support was more likely than other types of support to be identified by cancer patients as being most "helpful". Dunkel-Schetter, found that in excess of 90 per cent of a sample of cancer patients mentioned the giving of emotional support as one of the most helpful things that anyone had done (allowing them to air their fears and worries which in turn led to them "feeling better).

Revenson et al. [1983] in a similar study of 32 non-hospitalised adult cancer patients with a variety of cancer types found more varied results. Patients were interviewed at different points during their illness and its treatment and a number of measures of psychological adjustment and emotional support were made. The data suggests, that for patients not undergoing chemotherapy or radiation treatments or for those with very limited functioning this type of supportive behaviour may increase negative mood and decrease self perceptions of worth. No consistent relationship was found between support and physical limitation or between physical limitation and adjustment. This effect, therefore, evokes the possibility that supportive behaviours are complex and contain elements of "true" support as well as threats to autonomy and self worth. These patients had completed all available active treatment and the stress of the disease was

more chronic than short term. The results indicate that social support is a more potent stress buffer at times of crisis, presumably when the individual is receptive to it, rather than in situations where the stress is long term and synonymous with "nearness to death".

Revenson et al. [1983] conclude their study with "paradoxically, then, social "support" may be non-supportive and even unsupportable, in fact, it may at the same time constitute a source of stress and source of support"(p328). This complex and interactional view is shared by Dunkel-Schetter and Wortman [1982] who provide detailed evidence that social interaction with cancer patients is often coloured by ambivalence, pity and false optimism or at least, may be perceived by the patient as such. In this way, a seemingly positive social interaction may carry a negative overtone.

The multidimensional nature of social support was further validated in a study by Bloom and Spiegel [1984]. They interviewed 86 women with advanced breast cancer to determine the way in which well being and social functioning were affected by the social support that they received.

The authors found that the emotional support by family members had a positive effect on the women's sense of well being whereas the level of social activity did not. In addition, no relationship was found between emotional support and social activity.In other words, the impact of social support was highly specific.

The effects of emotional support have been examined in other disease entities with equivocal results. McIvor et al. [1984] studied a sample of 120 non-hospitalised patients who were suffering from the spinal cord form of multiple sclerosis (M.S.). They were particularly interested in the role of perceived emotional support as a "buffer", which might enable the M.S. patient to cope more effectively and deal more successfully with negative emotions, in particular depression.

The results demonstrated that those patients with high levels of perceived social support experienced much less depression. This result was not found in those patients who were more disabled, suggesting that in some circumstances social support is unable to act successfully as a buffer against stressful events.

Social support as non-support

Attempts at providing support for a person experiencing a life crisis are not always helpful. Problems in social relationships may occur because of the fear and stigma associated with illness, the absence of a set of social norms concerning appropriate behaviour with cancer patients or because trying to maintain a social relationship under extreme stress may be stressful in itself. Brickman et al. [1982] conclude a review of social support and coping with the statement that "social support may create a process of secondary victimization whereby victims are "victimized" once again by awkward or

ineffective efforts to help them"(p378). Revenson et al. [1983] echo this view and suggest the possibility that supportive behaviours may contain both elements of "true" support as well as an inherent threat to autonomy and self-worth.

A study by Peters-Golden [1982] for example found that individuals who perceived themselves as having received adequate social support reported heightened feelings of isolation, avoidance and feeling labelled as abnormal. These results are largely due to the fact that the family and friends of these patients avoided talking about the issues raised by the disease and its treatment yet still provided a form of support.

Wortman and Lehman [1985] investigated the difficulties in social relationships between healthy network members and individuals experiencing a major life crisis. Support behaviours most commonly identified as unhelpful were giving advice, encouragement of recovery and minimisation or forced cheerfulness regarding the situation. Particularly helpful were, contact with others experiencing a similar life crisis and the opportunity for open expression of feelings.

The results of these studies demonstrate that the type of social support should be clearly defined. From the literature concerned with emotional social support, (the perception that one is cared for and loved or has a confidant or intimate friend), the generalisation can be made that this type of support is related to decreased distress during times of life

crises [Bloom, 1982; Bloom and Spiegel, 1984; Gore, 1978; Holahan and Moos, 1981]. In contrast, other types of social support may have negative effects on emotional adjustment [Funch and Mettlin, 1982; Peters-Golden, 1982; Revenson et al., 1983].

Models Using Individual Differences

Summarising the research on this topic it appears that individual differences play a role in the relationship between health and social support, but the findings are inconsistent and weak. Individual traits probably have some impact on how people utilise social support yet to date no clear pattern has emerged regarding the most important ones and their true effects.

Some theorists have argued that the buffering effect of social support is influenced by personality traits [Lefcourt et al., 1984] . Other researchers have examined differences such as sex or gender [Levy, 1983], sex role [Roos and Cohen, 1987], Locus of control [Sandler and Lakey, 1982] and age [Turner and Wood, 1985] with equivocal results.

Social support and the family

Social support is a concept that is relevant to the family as well as to the patient with cancer [Northouse, 1984], they are also under stress from the illness and may need help to cope.

The question then arises as to whether their specific needs are different to those of the patient. The previous chapter has described the difficulty in separating the effects of factors such as social support and physical symptoms on the adjustment of family members [Goldberg et al., 1984; Cassileth et al., 1985; 1985a; Baider et al., 1986; 1989; Ell et al., 1988; Oberst and Scott, 1988]. This difficulty in part is due to a problem of definition and measurement of social support. Whereas for the patient social support has been specifically defined and emotional support found to be the most important in adjustment to illness [Wortman and Lehman, 1985]. Few studies exist in the area of the role of social support in family functioning.

As Northouse [1988] states in her review of social support and adjustment to breast cancer "although social support has been identified as an important factor in the adjustment of women with breast cancer, there has been virtually no research on the relationship between social support and the adjustment of husbands"(p91). This statement is true with respect to social support and the family in general.

Psychiatric conditions and in particular dementia have witnessed a rapid growth of interest regarding the influence of social support on the adjustment of the spouse [Gilleard et al., 1984]. Studies in this area have on the whole been inconclusive regarding the role of social support in ameliorating stress, however [Fiore et al., 1986]. The reasons for these equivocal results are thought to be due to

inconsistent measures and definitions of social support and a lack of measurement of stress and social support at varying time points throughout the illness [Morris et al., 1989]. It is not yet clear what type of social support facilitates the psychological adjustment of spouses in patients suffering from dementia [Morris et al., 1989].

Scant information is available relating to the type of social support that is most useful to the spouses of cancer patients. Baider and Kaplan de Nour [1984] found that both patients and spouses at high risk of developing psychological distress following the mastectomy were those with family environments that did not allow them to express their feelings openly. Those couples whose families allowed them to disclose and discuss their fears, worries and emotions were found to be at less risk of prolonged psychological distress.

Northouse [1988] replicated this study with a group of 50 mastectomy patients and their husbands. She assessed emotion immediately after surgery and again one month later using the social support questionnaire and measured psychological distress using the Brief Symptom Inventory. Both patients and their husbands who reported higher levels of social support reported fewer adjustment difficulties immediately after surgery and a month later. Husbands, however, perceived significantly less support from health professionals than patients throughout the course of the study but perceived similar levels of emotional support from family and friends to the patient. As Northouse [1988] concludes "the

findings of this study suggest that social support is an important factor not only for patients but also for their husbands during the immediate post-operative period"(p94).

Emotional support is clearly important for the patient and their spouse at least during the early phases of cancer. High levels of perceived emotional support appear to act as a "buffer" against the stress of an illness such as cancer. The evidence regarding social support and families is scarce. In particular, the role of social support in psychological adjustment at different time points during the illness "process" is far from clear. Further research is required to investigate this effect systematically and in more detail.

The measurement of social support

The measurement of social support is an important issue. In recent years, investigators have begun to realise the importance of employing carefully validated, reliable scales in its assessment. This has arisen as interest in the area has increased and as a result the number of available scales has grown. Unfortunately, many are not based on any theoretical perspective and assess vague, idiosyncratic aspects of the concept [Wortman, 1984].

The standardised scales described in the literature have for the most part been designed for use with the general population although some have been developed and validated with specific groups such as college students [Cohen and Haberman,

1955] or patients with multiple sclerosis [Brandt and Weinert, 1981]. Currently, there are no scales available which have been designed specifically for use among cancer patients.

In selecting a standardised scale to measure social support one must decide whether the structural aspects or the functional aspects are of prime importance. In the area of adjustment to illness, it has already been demonstrated that emotional support predominates. In recent years, a large number of scales have been developed to assess perceived social support, or the quality of social relationships. These scales differ considerably in format and mode of completion. Some consist of a number of items which require a forced choice response [Procidano and Heller, 1983] whilst others may involve a structured interview [Henderson et al., 1980] or the use of vignettes or stories [Turner and Noh, 1983]. The variability in the scales is considerable. Some measures are lengthy and time consuming to complete, for example the "Interview Schedule for Social Interaction" [Henderson et al., 1980] takes between 30-45 minutes to complete and consists of 52 items. Others are extremely brief such as the " The Instrumental Expressive Social Support Scale" [Lin et al., 1979] which contains nine items and takes between 3-5 minutes to complete.

One aspect of these scales that is particularly important is their psychometric properties. Many of the scales have never had their psychometric properties fully investigated. "The Social Support Index" [Bell et al., 1982] for example, has no

data available in terms of test-retest reliability, internal consistency or validity with respect to correlations with other social support scales. This also applies to a number of other scales including the "Social Network Index" [Berkman and Syme, 1979], the "Social Relationships and Activities Scale" [House et al., 1982] and the "Social Support Scale" [Blazer, 1982].

A further problem with these scales is the lack of applicability to the area of oncology. Many have been developed using American student populations or respondents from the general population who have, therefore been fit and healthy and for the most part under the age of forty; factors which immediately limit their use.

A number of scales, however, do show more robust psychometric properties as well as having been validated in populations of cancer patients or other patients confronted with life threatening illness.

Northouse [1988] developed a scale called the "Social Support Questionnaire" for use with mastectomy patients. It included questions related to having a person who listens to concern., who demonstrates understanding, who shows love and concerns, with whom the patient could discuss difficult issues honestly. The scale contains 40 items and subjects rate their responses on a five point likert scale from strongly agree to strongly disagree. It take approximately 15 minutes to complete the questionnaire. The psychometric data available

demonstrates high test-retest reliability (0.90-0.94) and high internal consistency (0.93). The intercorrelation with other scales such as the family environment scale [Moos et al., 1974] are, however, less impressive achieving correlations of between 0.44-0.56 with various subscales of the latter. The latter finding is currently being investigated further.

This questionnaire rates social support from a number of sources which include spouse, family member, friend, nurse and physician. The instrument is newly developed and further psychometric analysis is required in order to assess its reliability and validity as well as the efficacy of social support from the above sources.

One of the most widely used measures of social support is "the Inventory of Socially Supportive Behaviours" Barrera et al. [1981]. This scale has been found to reflect a number of meaningful categories of supportive transactions, such as the frequency and quality of helping behaviours including the provision of material aid, physical assistance, guidance, feedback, and social participation [Barrera and Amley, 1983; Walkey et al., 1987] . The scale contains 40 items and takes about ten minutes to complete. The reliability and validity of this tool have been found to be excellent (0.88-0.93) [Walkey et al., 1987] but unfortunately these validation studies have only been conducted using students as test subjects so that further work is required to validate its use in patient populations.

The expectation that this scale would aid in the prediction of positive adjustment to stress has not received empirical verification [Sandler and Barrera, 1984; Tetzloff and Barrera, 1987]. Cohen and Wills, [1985] postulate a number of reasons for this. First, the tool confounds the availability of support with the need for the use of support. A second difficulty is that the scales assesses support received in the recent past and how often it was given, rather than the individual's perception of support in the present. Finally, the scale designates supportive behaviours rather than allowing the individual to subjectively rate their own perception of the adequacy of supportive behaviours. A fundamental issue is the distinction between overt behaviours performed by members of a social network and their subjective impact on the recipient.

Perception of social support according to Cohen and Wills [1985] is important as the buffering qualities of support are cognitively mediated. This means that if a person perceives that they are loved, cared for and cherished and that in time of adversity a supportive network is available, then this can reduce anxieties concerned with coping alone or feeling isolated.

The "Perceived Social Support Scale" [Procidano and Heller, 1983] was designed to meet this need. The questionnaire is based on a theoretical perspective regarding the nature of social support, in particular the view held by Cobb [1976] who described social support as "information leading the subject to

believe that he is cared for and loved.....esteemed and valued....and belongs to a network of communication and mutual obligations"(p300). The scale uses a cognitive or attributional definition of social support to tap the subjects' perception of social support. This approach is consistent with current conceptualisations of coping which include a component concerned with appraisal of situations which are discussed earlier in this chapter [Folkman and Lazarus, 1980].

The "Perceived Social Support Scale" developed by Procidano and Heller [1983] is composed of two sub-scales, each comprising 20 declarative statements regarding the extent to which subjects believe that their needs for support, communication and feedback are being fulfilled by family or friends respectively. The whole scale of 40 questions takes approximately 8-10 minutes to complete.

The scale has been the subject of extensive psychometric investigation. Factor analysis has indicated that the two sub-scales are composed of single orthoganol factors [Sarason et al., 1987]. The two factors identified in these studies (family and friends) are consistent with the findings of Zimet et al. [1988] whose factor analyses of their own perceived support measure yielded "family", "friend" and "significant other" as independent factors.

The inclusion in the "Perceived Social Support Scale" (PSSS) of certain items reflecting provision of support by the subject to others is consistent with the finding of a relationship of reciprocity

and bi-directional support provision to adjustment [Maton, 1987].

Sarason et al. [1987] in a number of correlational studies using the PSSS, found that the scale measured concepts such as "feeling valued and esteemed". They concluded that the concept of perceived emotional support was more likely to predict well being and/or to buffer stress than other types of support. A finding consistent with those from a number of other studies [Barrera, 1986; Wethington and Kessler, 1986; Wilcox, 1981].

The early validation studies of the PSSS were carried out using populations of college students as subjects [Procidano and Heller, 1983]. These studies demonstrated that the two sub-scales (support from family and friends) were internally consistent (0.90). This finding has been replicated by other studies more recently [Ferraro and Procidano, 1986; Procidano et al., 1988] with Cronbach alpha coefficients ranging from 0.84-0.91.

The test-re-test reliability has similarly been ascertained by a number of studies over a one month period and produced correlations ranging from 0.8-0.86 [Ferraro and Procidano, 1986; Clair, 1988; Procidano et al., 1988].

The psychometric properties of the scale have also been tested using patients with multiple sclerosis and the family members of the alcoholic patients. The internal consistency in these

groups has been found to be very high (0.89-0.91) as has the test-re-test reliability (0.84) [Louis, 1986; Clair, 1988].

In addition to the above, normative data has been collected for 24 samples of subjects. These groups consist of 13 non-clinical samples, high school students [Sarason et al., 1987; Procidano et al., 1988], college students [Procidano and Heller, 1983; Ferraro and Procidano, 1986; Lyons et al., 1988], adolescents [Clair, 1988], and mothers of young children [Wade and Procidano, 1986] as well as 11 samples of clinical subjects i.e. subjects with a medical or psychiatric diagnosis. The clinical samples include patients with multiple sclerosis [Louis, 1986; McIvor et al., 1987], diabetes [Lyons et al., 1988], elderly patients with various medical conditions [Zelles, 1988], male partners of patients undergoing termination of pregnancy [Zelles, 1988], chronic psychiatric patients [Lyons et al., 1988], hospitalised patients attempting suicide [Frigon, 1986], drug addicts [Grey et al., 1986] and women undergoing mastectomy [Jones and Reznikoff, 1989]. Normative data have thus been derived from 848 non-clinical subjects and 794 clinical subjects. A Comparison of the means of these normative populations reveal highly significant differences between them (Figure 4). The clinical samples have lower levels of perceived social support than the non-clinical ones (lower PSSS scores= lower levels of perceived social support). This data is currently undergoing further analysis by one of the authors of the perceived social support scale in order to clarify the reasons for these differences (Procidano, 1990; personal communication).

Figure 4.

A comparison of means of PSSS (friends) and PSSS (family) in clinical and non-clinical populations (normative data).

	PSSS (Family)	PSSS (Friends)
Clinical Sample	9.25	10.70
Non-Clinical Sample	12.70	13.62
	(p<.001)	**(p<.001)**

The PSSS has been used to examine the relationship between social support and adjustment to a variety of physical illnesses. The hypothesis that social support acts as a "buffer" in mediating the effects of stressful events predicts a negative relationship between support and psychological distress. This has been confirmed in patients suffering from multiple sclerosis, where those patients with higher social support were found to be less depressed [McIvor et al. 1984; Louis, 1986] and in adolescents with alcoholic fathers [Clair, 1988]. The relationship was found to exist with respect to support given by both family members and friends.

In summary, the evidence available on the PSSS suggests that it is the best tool currently available to examine the relationship between social support and adaptation to serious illness.

Methodological problems in the study of social support and adjustment to stress

In addition to the specific issues raised earlier in this chapter, namely the importance of defining the type of social support of interest and selecting the appropriate scale for its measurement, a number of other issues need to be considered.

1. In order to assess the buffering effects of social support it is important to define the stress situation (ie that which is to be buffered against). Whilst this statement may seem obvious, a number of researchers have approached the problem of social support and stress by measuring life events in groups of subjects using questionnaires and then correlating social support with psychological distress [Wilcox, 1981a]. As stressful life events increase social support is hypothesised to reduce the level of distress in individuals.

One of the methodological difficulties inherent in this approach is the fact that the most commonly used life event questionnaire, the social readjustment rating scale [Holmes and Rahe, 1967], sums a number of different life events. The problem with this approach is that different types of stressful events benefit from differing types of social support., (practical support may be the best way to help someone who is moving house and emotional support may be the obvious choice to help someone coping with a divorce). The findings from this type of approach may be equivocal and confusing thus distorting our

understanding of the the effect of social support. A specific type of stressor, such as diagnosis of cancer may result in a more complete understanding of the relevance of social support by reducing some of the potential variance created by the "life events" approach.

2. In examining the impact of support in mediating psychological distress in a stressful situation it is important to select a reliable and well validated measure of distress as this may be the principle outcome variable. In practice the assessment of psychological distress involves the measurement of anxiety and depression. In the field of psychosocial oncology this requires extra consideration (discussed in a previous chapter).

3. Many early studies showing a correlation between social support and health outcomes have been interpreted as evidence for a causal relationship between the variables measured, for example in facilitating adjustment [Holahan and Moos, 1981; Thoits, 1982; Wortman, 1984; Cohen and Syme, 1985]. As numerous authors have claimed, however, other explanations may account for these findings and contribute to distress. These factors may include such things as the presence of physical symptoms, personality variables, effects of treatment on specific areas of life, the presence of a previous psychiatric history and coping style. It is imperative, therefore, that social support is examined within the context of the patients' illness, personality, and lifestyle as well as that of the family.

4. Social support may have differential effects in mediating distress over the course of an illness such as cancer. It is therefore important in conducting a study in this field to take account of this perspective [Wortman, 1984] by implementing assessments throughout the course of the disease and its treatment.

5. In order to examine the "buffering" effects of social support, any instrument used must measure the subjects' perceptions of the adequacy of that support. This is in marked contrast to the approach taken in other studies where researchers themselves may interpret the adequacy of support to the recipient [Cohen and Wills, 1985].

In conclusion, therefore, this review reflects a growing appreciation of the complexity of the social support construct and the need for greater conceptual and research specificity. The data relating to a stress "buffering" effect of social support in the area of psychosocial oncology are equivocal and require further investigation. Social support in relation to the family is an area that has not been dealt with adequately and in particular its role in facilitating coping responses and mediating stress. It is clearly an area that has attracted interest over the past decade and in the future has the potential to contribute to the understanding of factors that may positively influence the psychological well-being of individual patients as well as their families. As Funch and Mettlin [1982] conclude, more research is essential in this

area, if we are to understand the relationship between social support and stress, "Increased understanding along these lines would not only make a valuable theoretical contribution, but could have practical applications for improving the medical care process and illness outcomes"(p97).

Chapter Six

LITERATURE REVIEW:SUMMARY AND CONCLUSIONS.

The previous chapters describe and discuss the impact of cancer and its treatment on both the patient and their family. A number of conclusions can be extracted from this review and the deficiencies in this body of literature can be identified.

1. Cancer is a disease consisting of stages and is, therefore a "process" through which the patient passes from diagnosis followed by treatment to death or "cure".

2. Patients may experience a range of emotions during the illness and its treatment. Some of these emotions may be regarded as "normal" and others as "abnormal", such as clinical anxiety and depression.

3. Anxiety and depression can be modified by factors such as the presence of physical symptoms, personality, the presence of supportive relationships, age, previous psychiatric history and religious affiliation.

4. The results of studies investigating the psychological impact of cancer on the patient are often confounded by using heterogeneous groups of patients with different cancer types undergoing different types of treatment.

5. The results of these studies may be further complicated by the failure of researchers to use standardised assessment scales which have been found to be valid and reliable in the field of oncology for the detection of anxiety and depression.

6. Cancer effects other areas of patients' lives such as sexual relationships, family relationships and employment.

7. Cancer effects the family as well as the patient, yet there has been very little research on the psychosocial impact of the illness on family members.

8. Social support has been found to facilitate psychological adjustment of patients to life threatening illness, in particular perceived social support.

9. The role of perceived emotional social support in reducing distress and facilitating the psychological adjustment of family members to a life threatening illness has not been adequately studied.

10. A concept such as perceived emotional social support is often inadequately assessed using unstandardised scales.

11. Social support may have differential effects in mediating distress over the course of an illness, this perspective is, as yet, inadequately researched.

The deficiencies identified in this review of the literature can be corrected using the following:

1. Longitudinal studies of cancer and its treatment on patients and their families.

2. The use of standardised assessment tools that are reliable and valid in the field of oncology.

3. A homogeneous group of cancer patients undergoing similar treatments.

4. The assessment of a range of variables: physical symptoms, side effects of treatment, social and demographic variables.

5. Assessing the impact of the illness on the lives of the patient and their family.

6. A systematic evaluation of the role of perceived emotional support in adjustment to cancer.

The correction of these shortcomings would enable a comprehensive picture of the impact of cancer on the patient and their family over the course of the illness to be obtained. Such a study would provide useful information in furthering our understanding of the psychosocial impact of the disease as well as planning interventions for those who are vulnerable. As Freidenbergs et al. [1981-82], conclude in their review of living with cancer, "It is hoped that the plight of the cancer

patient will be increasingly understood and that appropriate and effective intervention methodologies will soon be developed"(p322).

Chapter Seven

METHOD

Local background to the study

In order to study a homogeneous group of cancer patients experiencing similar management and treatment, a specific type of cancer was selected. Lung cancer proved to be an ideal choice for a number of reasons. Firstly, there were suitable numbers of available subjects treated in the department of clinical oncology at the Western General Hospital, Edinburgh. Secondly, the medical management of these patients was similar due to a number of drug trials using specific cytotoxic agents being conducted in the department at the time. Finally, lung cancer is a disease with a relatively short median survival time (12-14 months), as described in Chapter One, the whole "process" can be studied from a psychosocial perspective in a time scale compatible with a finite research project.

Patients referred to the clinical oncology unit at the Western General Hospital in Edinburgh have been thoroughly investigated before their diagnosis is confirmed. During an initial visit to an out-patient clinic, the patient and their family are able to discuss with one of the consultants issues

such as the diagnosis, prognosis, treatment options, side effects of treatment and so on. Following this visit and if patients agree to treatment they are admitted to the appropriate ward to commence chemotherapy. The type of chemotherapy which patients receive is dictated by several factors, primarily the type of tumour following biopsy and secondarily by the physical condition of the patient.

Patients then embark on a specified number of courses or cycles of treatment. This is often referred to as "active" treatment as the chemotherapy given during this time is the "optimum" dose recognised to reduce the tumour. The progress of treatment is monitored prior to each course of chemotherapy using chest X-rays by which the size of the tumour can be assessed, a variety of different blood count parameters are evaluated as well as performance status and body weight. These are routinely recorded by the medical staff on the ward when the patient is admitted for each treatment course. The performance status scale used in the department is the Eastern Co-operative Oncology Group (ECOG) scale [Zubrod et al., 1960], (see Appendix 2). This provides a five point scale of functional status in contrast to the 10 point Karnofsky Scale and is often used in cancer treatment trials as it is brief, easy to use and precise [Fayers and Jones, 1983; Maguire and Selby, 1989].

Following the completion of chemotherapy patients return on a monthly basis to the hospitals' out-patient clinic, for "follow-up" observation. During this period they undergo a chest X-ray

and clinical examination at each visit, they are, therefore, receiving no treatment for their disease but are subject to close physical monitoring.

During this time the patient may present with troublesome symptoms. These may be manifested in various way such as increasing breathlessness, pain in various parts of the body, headache, dysphagia or hoarseness to name but a few. These signs and symptoms may indicate that the disease has recurred and spread. At this time the physician may decide that the disease is no longer "curable" but due to the debilitating nature of the symptoms, palliative treatment is required. This is treatment designed to reduce the effects of the symptoms and thus improve the patient's quality of life. It is seen as a temporary measure giving the patient a period of respite. Most dictionary definitions of the word "palliate" refer to the concept of alleviation without curing and in fact the word is derived from the latin expression *"palliare"*, meaning "to cloak".

Palliative treatment in the case of lung cancer usually involves radiotherapy although on occasion palliative chemotherapy may be employed. Patients being given radiotherapy are usually prescribed a course of radiotherapy involving a specified number of individual treatments or "fractions" given over a specified time period. Radiotherapy is the use of high energy rays to "kill" cancer cells. Patients receive radiotherapy to specific parts of their body to alleviate symptoms. For example to the chest to improve breathlessness or to the back

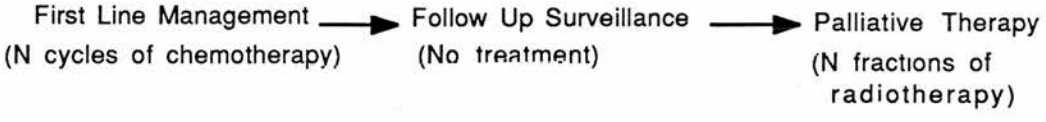
to help pain. The treatment causes side-effects and their type and severity will depend on the part of the body being treated, the dose of radiotherapy and the way the fractions are divided.

Following palliative radiotherapy treatment, patients may be relatively well for a period of time and then inevitably succumb to their advancing disease. This period of the patients' illness is almost inevitably lost to the hospital and the care is provided by the patients general practitioner or the hospice.

The "process" or "trajectory" of a patient with lung cancer treated in the clinical oncology unit at the Western General Hospital, Edinburgh may be summarised in the Figure 5.

Figure 5

"Process" or "Trajectory" of the patient with lung cancer.



Lung cancer: Cell type and chemotherapy.

A number of different chemotherapy regimens were available to patients in the "active" phase of treatment. These were

dependent on the histological type of the patients' disease as well as their physical state.

Non Small Cell Lung Cancer

Patients with non small cell lung cancer received a combination of two drugs: alfa 2b interferon (3 million units or 5 million units) and cis-platinum at 100mg/m^2. This combination consisted of the interferon being given three times weekly and the cis-platinum given every three weeks. Patients received either two courses or four courses of this drug combination.

The side effects of this combination include severe nausea and vomiting, nephrotoxicity, myelotoxicity, ototoxicity, peripheral neuropathy and hypomagnesaemia related to the cis-platinum. The side effects of interferon include "flu like" symptoms, fatigue, drowsiness, impaired concentration, slowness of cerebration, anxiety and depression.

Small Cell Lung Cancer

Patients with small cell lung cancer received one of three different cytotoxic combinations:

1. A combination consisting of methotrexate (200mg/m^2), adriamycin (50mg/m^2), cyclophosphamide(1mg/m^2), VP16-213 (120 mg/m^2). The side effects of this combination include alopecia, mouth ulcers, gastro-intestinal upset, severe nausea and vomiting, peripheral neuropathy, hypertension, cardiotoxicity, bone marrow suppression, tiredness and

lethargy. This was the most aggressive combination of drugs given to patients with small lung cancer it was commonly referred to as MACE which were the first letters of the component drugs.

2. A combination consisting of methotrexate (200mg/m^2), cyclophosphamide (1mg/m^2), VP 16-213 (120mg/m^2).
The side effects of this combination included alopecia, mouth ulcers, gastro-intestinal upset, mild nausea and vomiting, peripheral neuropathy, bone marrow suppression, tiredness and lethargy.
This combination of drugs was commonly referred to as MCVP16, which were the first letters of the component drugs in the regimen. Patients who received this combination were those patients who had a history of cardiac problems or who were found to have cardiac abnormalities on routine electrocardiogram monitoring.

3. The least aggressive drug combination used was vindesine (3mg/m^2) and VP 16-213 (120mg/m^2).
The side effects of this combination included peripheral neuropathy, constipation, minimal alopecia, hypertension, mild nausea and vomiting and bone marrow suppression. Patients who received this combination were patients who were the least healthy in that the doctors judged them to be too frail to received either of the other two combinations.

Patients receiving the treatments described above spent between three and four days in hospital receiving infusions of

the cytotoxic agents during this time. All courses of drugs were repeated at 21 day intervals for a specified number of courses.

STUDY AIMS

The aims of this study are to assess patients and their primary carers at different stages in the illness "process" in order:

1. To describe the psychological state of patients at each stage.

2. To describe the relationship between the psychological state of a group of cancer patients and that of their primary carer.

3. To identify factors contributing to psychological distress in patients and primary carers.

4. To assess the impact on their psychosocial function.

5. To evaluate the role of perceived emotional social support.

6. To assess change in social support between different stages of the illness.

7. To identify predictive factors in the development of psychological distress.

* In the majority of cases the primary carer was the spouse of the patient.

Hypotheses to be tested

In addition to the aims of the study, a number of hypotheses can be generated from the literature review:

1. There will be no significant difference in levels of anxiety and depression in patients at different stages of the illness and its treatment.

2. Those patients with greater levels of physical symptomatology will experience greater levels of anxiety and depression.

3. Those patients with high levels of perceived emotional social support will have lower levels of anxiety and depression.

4. The treatment of lung cancer will adversely affect other areas of patients' lives.

5. There will be no difference between the levels of anxiety and depression in patients and the levels of anxiety and depression in their primary carers.

6. Statistically significant correlations will be found between anxiety and depression levels in patients and their primary carers.

7. Statistically significant correlations will be found between physical symptomatology in patients and anxiety and depression in their primary carers.

8. Primary carers with high levels of perceived emotional social support will have low levels of anxiety and depression.

9. The treatment of lung cancer will adversely affect other areas of primary carers' lives.

10. The lives of patients and their primary carers will be equally adversely affected by lung cancer and its treatment.

11. Anxiety and depression in both patients and their primary carers will be explained by an interaction of low social support, high physical symptomatology and anxiety and depression in the 'significant other'.

Pilot study

The final study design described incorporating three groups of patients and their "primary carer" was developed from an initial pilot study. A longitudinal study of lung cancer patients conducted in the department of Clinical Oncology had demonstrated that it was possible to interview and assess lung cancer patients at regular intervals following diagnosis. A high level of compliance was obtained from these subjects thus enabling a comprehensive picture of their illness/treatment "process" to be obtained. It was hoped to use a similar design with the "primary carers" of lung cancer patients using the assessment battery described. The assessments were initially planned at monthly intervals with the "carers" but subjects reported that they could not cope with this level of investigation, five "carers" were approached but following the third administration of the battery, all five had withdrawn. As a result of this problem, the assessment interval was changed to a three monthly cycle. Even this level of investigation proved to be too demanding and a further six subjects withdrew following two administrations of the assessment battery. The pilot study consisted of 12 subjects. No statistical analysis was performed due to the attrition rate described above and, as a result, none of the data was used in the final study design.

This pilot study indicated the stressful nature of lung cancer for the carer and a modification to the study design was essential in this light. In order to overcome this difficulty a single assessment was introduced assessing groups of patients and their "primary carers" on a single occasion at different

points during the disease yet with a common experience of the treatment "process".

The study design about to be described was felt to be the most accurate psychosocial investigation of lung cancer and its treatment which could have been undertaken given the limitations imposed by the early pilot study, although it is clear that the description of this "process" will be less than optimal. The resulting study, therefore, uses a "stage" model of the illness rather than a "process" model.

Definitive Study

Subjects

The subjects selected for this study were a consecutive series of patients.
The subjects selected for this study (240 in all), were patients with a diagnosis of either small cell lung cancer or non small cell lung cancer (120) and their primary carer (120). It became evident, however, that some patients did not have a next of kin but were going be cared for by friends or more distant relatives. In view of this, the concept of "next of kin" was replaced by the term "primary carer" i.e. the person who undertakes to provide the majority of the physical and emotional care of the patient.

Inclusion Criteria

1. Patients with a proven diagnosis of lung cancer and treated on one of the above specified therapeutic drug trials (MACE, MCVP16, Vindesine/VP16).

2. The "primary carers" of the above.

3. Patients and carers able to give informed consent.

Exclusion Criteria

1. Subjects not wishing to take part.

2. Subjects, who in the opinion of the Consultant responsible were unfit to take part either physically or psychologically.

3. Subjects without a "primary carer".

4. Non-English speaking subjects.

5. Subjects with a previous history of malignancy.

6. Subjects with current evidence of psychiatric impairment.

The current study aimed to describe the impact of the disease and its treatment at different points during the "process" on patients and their "primary carers". In order to take account of the three phases of the illness previously described three groups of patients and their "primary carers" were identified.

Group 1: Patients receiving active treatment.

Patients were identified and interviewed at the mid-point of their chemotherapy regime. If, therefore, it was anticipated that a patient would receive six cycles of chemotherapy, they would then be interviewed following their third cycle. At the same time the identified "primary carer" was interviewed but in a separate room from the patient. The mid-point of the "active" treatment period was selected in order to avoid the contaminating effects of the initial impact of diagnosis.

Subjects were approached during the admission to the oncology ward prior to the mid-point of treatment. At this time the study was explained and the printed information sheets given out. Only those subjects who agreed to participate in the study on their next admission were interviewed. The interviews were conducted before the commencement of treatment on the relevant admission. In all cases, the "primary carer" visited the hospital at some point during the patients admission and they were approached during this time and the study explained.

Group 2: Patients on follow-up observation.

This group of patients and their "primary carers" had already complete their anticipated number of cycles of chemotherapy. They had been subject to a period of follow-up observation for at least one month and had therefore already visited the out-patient clinic on a previous occasion during this period of monitoring. On their first visit to the clinic following the completion of treatment subjects were approached and the study explained to them. The printed information sheet was given to them and only those who agreed to participate were interviewed at their next visit to the clinic. In the event of a patient attending the clinic alone on the first occasion, an information sheet was given to them for their "primary carer" and only those consenting patients who attended clinic with their "primary carer" on their next visit were interviewed.

Group 3: Patients receiving palliative treatment.
Patients and their "primary carers" in this group had completed their anticipated number of cycles of chemotherapy and then entered a period of follow-up observation. During this latter period they had developed debilitating symptoms precipitating referral for a course of palliative radiotherapy treatment.

On the first visit to the hospital to plan palliative treatment patients were encouraged to bring their carers. On this first occasion following the decision to instigate palliative therapy, patients and their "primary carers" were approached, the study explained to them and printed information sheets given to them. Those subjects who agreed to participate were interviewed at the mid-point of their treatment. If, for example, ten fractions of radiotherapy were prescribed for a patient then they would be interviewed following the fifth fraction.

A review of the numbers of patients seen in the department of clinical oncology in the previous year with a diagnosis of either small cell lung cancer or non small cell lung cancer enabled a realistic number of subjects to be calculated. The numbers of patients and their "primary carers" likely to be recruited are shown in figure 6.

Figure 6
Numbers of subjects likely to be recruited at each stage of the illness.

	Active Treatment	Follow up observation	Palliative treatment
Patient	40	40	40
Primary carers	40	40	40

The subjects recruited for this study, therefore, have been derived from three groups of patients representing different stages of lung cancer and its treatments. Subjects in each group have been interviewed on a single occasion and each group has followed a similar path, in that those patients in the follow-up observation group have been given "active" chemotherapy and those patients in the palliative treatment group have received "active" chemotherapy and experienced a period of follow-up observation.

CONSENT

The nature and purpose of the project was explained to the subjects and an information sheet given to them to read concerning the study. Only those patients who were capable of giving written informed consent were included in the study, and none were excluded on these grounds (copies of the information sheet and the consent form are included in the Appendix 1 of this thesis).

Procedure

A battery of scales and an interview schedule which take approximately sixty minutes to complete was assembled, to be completed by both the patient and their "primary carer". These scales are shown in Figure 7, and a description and explanation of each follows.

Figure 7
Assessment scales completed by lung cancer patients and their "primary carers".

Domain	Patient	"Primary Carer"
Demographic data	Brief Interview Schedule	Brief Interview Schedule
Mood	HAD	HAD
Psychiatric Screening	*No Assessment*	GHQ
Adjustment to Illness	PAIS	PAIS
Personality	EPI	EPI
Social Support	PSSS (Family & Friends)	PSSS (Family & Friends)
Symptoms & Side Effects	Symptoms & Side effects Scale	*No Assessment*

(HAD= Hospital Anxiety and Depression Scale, PAIS= Psychosocial Adjustment to Illness Scale, EPI= Eysenck Personality Inventory, PSSS= Perceived Social Support from Family and Friends, GHQ= General Health Questionnaire).

1. The Brief Interview Schedule

The interview schedule was devised by the author (see Appendix 2). It assesses a range of demographic variables including age, sex, marital status, occupation and past medical and psychiatric history. It is also concerned with issues such as attitudes to illness and treatment as well as fears and worries resulting from this. The schedule also assesses

variation in a number of areas of patients and their "primary carers" lives. These include changes in personal relationships, communication, social interaction, leisure activities, perceived social support from family and friends and domestic circumstances.

The researcher conducted similar interviews with both the patient and their "primary carer". The interview schedule took 10-15 minutes to complete for both the patient and their "primary carer".

The questions included in this schedule were devised in order to take into account some of the methodological weaknesses inherent in the existing research literature. The data from this schedule were not independently validated: they merely formed some descriptive insights into the experiences of the subjects and therefore should be interpreted with caution.

2. The Hospital Anxiety and Depression Scale (HAD), [Zigmond and Snaith, 1983]

The HAD scale is a self assessment scale which was designed to detect the mood disorders of anxiety and depression in non-psychiatric populations attending hospital medical out-patient clinics. The scale is composed of 14 items, 7 for anxiety and 7 for depression. Subjects are instructed to "place the tick in the box opposite the reply (to each item) which comes closest to how you have been feeling in the past week".

The scale differs from other self-assessment mood scales in a number of important respects:

1. Items which reflect symptoms likely to occur in a physical illness such as insomnia or loss of appetite (which are included in other psychiatric assessment scales) have been excluded. The scale, therefore, concentrates on psychic manifestations of anxiety and depression rather than somatic ones.

2. The concepts of anxiety and depression have been separated. Some scales fail to do this such as the Hamilton depression rating scale [Hamilton, 1967] where symptoms of both appear in a single scale.

3. The concept of depression is focussed on the anhedonic state, an important indicator of depression in physical illness [Snaith, 1987].

4. Items such as "suicidal pre-occupation" or "fear of losing one's mind" have been excluded in order to make the scale acceptable to physically ill patients. None of the items imply that he or she necessarily suffers from a psychiatric disorder and indeed Snaith developed the scale to detect the presence of relatively mild degrees of mood disorder as well as "case" levels.

5. The scale is brief, readily comprehensible and easily completed by patients.

6. The scale is appropriate for use with healthy individuals in the detection of mood disorder and is therefore suitable for

use with the patients' "primary carer" [Snaith, 1987 personal communication].

The HAD takes approximately five minute to complete and is easy to score. In fact the scale is self scoring on a carbon copy behind the front sheet. Each item is rated on a four point scale (0-3) and the raw scores for each sub-scale are summed. The "caseness" of each individual's total score can then be calculated, the cut-offs for each category are shown below.

HAD "cut-off" scores for both anxiety and depression [Zigmond and Snaith, 1983].

0-7 Non-case

8-10 "Borderline" case

11-21 "Case"

Snaith [1987] has advocated that should a "case" level score persist for a period of a month or longer then the patient should be considered for some form of psychiatric or psychological intervention a view also shared by other clinicians [Maguire, 1984].

The reliability and the validity of the HAD scale have received considerable attention in a variety of different health care settings. Zigmond and Snaith [1983] found that the concurrent validity for the sub-scales on the HAD and the clinical rating of psychiatrist were +0.70 for depression and +0.74 for anxiety,

both being highly statistically significant. The false positive and false negative rates were also reported in this paper. They were found to be 1 per cent false positives and 1 per cent false negatives for depression and 5 per cent false positives and 1 per cent false negatives for anxiety.

Since the original paper concerning the development of the HAD scale the scale has been thoroughly investigated. Aylard et al. [1987] reported that the two sub-scales of the HAD were measuring different aspects of mood disorder as the correlation between the two was only +0.04. They also reported significant correlations of the sub-scales with those patients known to have definite mood disorder (depression =0.77, anxiety =0.67). Moorey et al. [1991] on the other hand have found that the factor structure of the scale is stable and the two factors in the scale are correlated (r=+0.50). El Rufaie [1987] reported high levels of correlation with clinical psychiatric interviews in a group of 50 Saudi patients. The author reported correlations of +0.88 for depression and +0.86 for anxiety both highly significant results.

Barczak et al. [1988] conducted a study of 100 patients attending a genito-urinary clinic. They compared the HAD scale against the structured clinical interview for DSMIII in terms of its sensitivity and specificity using the cut-off scores recommended by Zigmond and Snaith [1983]. They found that the recommended cut-offs gave optimum specificity and sensitivity. The specificity was 94 per cent and 68 per cent for depressive disorders and anxiety disorders respectively and

the sensitivity for each was 82 per cent and 70 per cent respectively. Andrews et al. [1988] replicated this result in a study using a population of patients with inflammatory bowel disease. The issue of sensitivity and specificity of the HAD scale has recently been the subject of some discussion and debate, which as yet remains unresolved [Ibbotson, 1988; Hopwood et al., 1991a; 1991b].

The HAD scale is, therefore, ideal in the assessment of mood disorders in patients with physical illness. Recently, researchers have found that it lends itself to use with cancer patients. Slevin et al. [1987] reported that the scale was acceptable to patients even when required to complete it several times in a single day. Slevin reported that only the patient can accurately measure his or her subjective state and that the HAD is an ideal tool for such an assessment as subjects complete it themselves.

Morris and Royle [1988] employed the HAD scale in a study of women undergoing surgery for breast cancer and their husbands. The HAD was completed pre-operatively and then at 2,3, and 12 months post-operatively without difficulty by either group. As Aylard et al. [1987] conclude " the HAD scale is a valid instrument in the setting for which it was designed i.e. the detection and assessment of the mood disorders of anxiety and depression in hospital out-patient clinics. The very small proportion of misclassifications with the scale

suggests it may be used as a preliminary screen for disorder in future studies and also in clinical practice"(p267).

3. The General Health Questionnaire GHQ (28 item), [Goldberg and Hillier, 1979]

The General Health Questionnaire was originally developed to aid in the detection of psychiatric disorder in community and primary care settings. It was devised as a self administered screening tool [Goldberg, 1972]. Since its introduction it has been subject to a number of validity studies used for prevalence estimation applied in a number of cultures and languages and evaluated in prescriptive screening [Tarnopolosky et al., 1979; Henderson et al., 1981; Benjamin et al., 1982; Radovanic and Eric, 1983; Banks, 1983; Chan and Chan, 1983; Skuse and Williams, 1984]. In addition, several forms of the GHQ have been produced ranging in length from 12 to 60 items intended for a variety of needs. The GHQ 28 is a scaled version of the questionnaire and is intended for research purposes [Goldberg and Hillier, 1979].

The GHQ 28 was developed from the longer 60 item scale by subjecting 523 completed questionnaires to a principal component analysis. This analysis resulted in eleven significant factors accounting for 63.4 per cent of the total variance. A further varimax rotation resulted in four factors accounting for 59 per cent of the total variance. These four sub-scales consisted of somatic symptoms, anxiety and insomnia, social dysfunction and severe depression.

Questions refer to the past few weeks and subjects score each item of behaviour on a scale ranging from "better then usual" to "much worse than usual". The 28 items of the scale takes approximately 5-10 minutes to complete. From the completed questionnaire item scores are summed for each sub-scale or a total single score calculated which acts as a severity score. The total single score can be used if the scale is intended as a screening test. A threshold score of 4/5 has a sensitivity of 85.6 percent and a specificity of 86.8 per cent [Goldberg, 1978]. The correlation between the total score and the overall clinical assessment by a psychiatrist using a standardised clinical interview is +0.76 [Goldberg, 1978]. Boardman [1987] reported that the GHQ 28 was more reliable and more stable in detecting psychiatric morbidity than general practitioners.

The GHQ has been extensively validated in general practice populations [Goldberg et al., 1976; Johnstone and Goldberg, 1976; Benjamin et al., 1982; Boardman, 1987], it has also been validated for use in general medical wards in hospital settings [Maguire et al., 1974] as well as in the specialist settings such as dermatology clinics [Hughes et al., 1983]. The GHQ has also been found to be a useful and valid screening instrument in the general population [Tarnopolosky et al., 1979; Hobbs et al., 1983; Hobbs et al., 1984], making it ideal for use with the "primary carers" of lung cancer patients.

Hardman et al. [1989] found that when used as a screening tool with patients on a medical oncology ward had an unacceptably high level of false negative (21%) and false

positive (34%) identification. This unacceptably high level of error was primarily due to the somatic items included in the scale. In order to minimise these errors of detection subtle manipulations of the threshold scores were required using "relative operating characteristic analysis" and the introduction of a "gold standard" test for psychiatric detection. Conversely, Ellman et al. [1989] found that the GHQ 28 could successfully be used as a screening instrument in women attending a clinic for routine breast cancer screening. The authors found that the scale was brief and acceptable to the 302 women attending for a potentially anxiety provoking procedure as well as being a valid measure for use in this population. Some doubt remains, however, concerning the use of the GHQ with oncology patients and so in the current study its use was confined to the primary carers.

4. The Psychosocial Adjustment to Illness Scale (PAIS), [Derogatis, 1976, 1983].

The PAIS is comprised of 46 items designed to assess the quality of a patients adjustment to an illness and its treatment. The scale can be used as either a semi-structured interview or in a self report format and takes the patient about 15 minutes to complete. Each item in the PAIS is rated on a four point scale (0-3) of adjustment and the reference time period for each response is the past 30 days. For example:

During the past 30 days, have you lost any time at work (school) due to your illness?

Score

(0) [ ] a) 3 days or less
(1) [ ] b) 1 week
(2) [ ] c) 2 weeks
(3) [ ] d) more than 2 weeks

The respondent is instructed to tick the appropriate box and scores assigned to each are shown in brackets.

The scale is divided into seven primary domains of adjustment with a specific number of items in each domain, as shown in Figure 8.

Figure 8

Structure and scoring of the PAIS Scale.

Pais Domains	Item Number	Maximum Score possible
1 Health Care Orientation	8	24
11 Vocational Environment	6	18
111 Domestic Environment	8	24
1V Sexual Relationships	6	18
V Extended Family Relationships	5	15
V1 Social Environment	6	18
V11 Psychological Distress	7	21

The scale can be reported as a series of results from each "domain" or as a total "Global Adjustment to Illness" score. The

higher the rating the poorer the patients adjustment to their illness.

The raw scores obtained from each domain can be converted to a standardised "T-score" and then summed to generate a PAIS total score. The "T-score" is calculated by reference to specific norms available in the test manual. These include normative data for lung cancer patients, renal dialysis patients, cardiac patients and mixed cancer patients. However, there is also a non-normal conversion table for subjects who are not easily compared to the available normative groups. The PAIS is suitable for use with spouses of patients or other relatives (in semi structured interview or self report form) in order to look at their quality of adjustment. Minor modifications are made to the question format, but screening and translation of scores are conducted in the same way. In some situations normative comparisons have been found to be difficult to make (eg with healthy subjects) and the authors of the scale recommend that the raw scores of both the patient and the relative should be used. This method has also been found to be more precise "since it avoids the rounding error associated with standardised scores"(p19), [Derogatis, 1983].

The reliability and validity of the PAIS have been subjected to extensive scrutiny. Morrow et al. [1978] in a study of 37 patients who had been treated for Hodgkin's disease in the previous two years and 38 parents whose children had been treated for Hodgkin's disease or solid tumours. The inter-rater reliability in this study for the total scale score was found to

be +0.83. The subtest domains were found to be relatively independent from one another but still contributed to the total score demonstrating the construct validity of the scale. The criterion validity of the individual domains was also assessed by cross correlating them with other well validated scales. For example, the psychological distress scale of the PAIS was found to correlate significantly with the Spielberger State Trait Anxiety Inventory, with observer rating of anxiety on the Symptom Check List 90 Analogue Scale and the Beck Depression Inventory indicating strong support for the criterion validity of this sub-scale.

Derogatis [1983] reports the results of a factor analysis of the PAIS based upon the assessments of 120 patients with lung cancer. Seven substantive domains were identified in this analysis accounting for approximately 63 per cent of the variance in the orthogonal rotated factor matrix. These seven domains equated with the seven domains of the PAIS, factor 1 accounted for 18 per cent of the variance and the remaining factors accounted for 10, 9, 8, 7, 7, and 5 per cent respectively. This data supports the hypothesised structure of the scale.

The PAIS has also been validated for use with patients with other medical conditions. Kaplan de Nour [1982] used it in a group of 102 patients undergoing chronic haemodialysis. She concludes that; "the PAIS is indeed an adequate scale for obtaining measured information about patients' global adjustment as well as their adjustment in specific areas.....it was comparatively easy to administer to a fairly large

population, it covers several aspect on adjustment, and good correlations were found between patients' reports and the physicians assessments"(p20).

Folks et al. [1986] validated the PAIS in a group of 96 patients who had recently undergone coronary artery bypass surgery. They conclude that use of the PAIS to study patients undergoing procedures such as CABG (coronary artery bypass grafting) is advantageous in that the instrument is brief and simple to administer, yet it reveals psychosocial functioning in several dimensions. The seven psychosocial domains assessed by the PAIS in the latter study were found to convey effectively and accurately the patients global adjustment to the disease, as well as the therapeutic impact of coronary artery bypass surgery. Dialysis patients and cardiac patients are two other groups for whom norms are available from the early development studies of the scale.

The PAIS has also received substantial validation with cancer patients. Cain et al. [1983] used it successfully to assess the psychosocial impact of different types of gynaecologic cancer. The scale proved useful in examining the impact of the illness on specific areas of the subjects lives and in combination with a number other scales provided a comprehensive description of the impact of different types of gynaecologic cancer and also of varying degrees of severity of disease.

Gilber and Kaplan de Nour [1989] in a study of 106 cancer patients undergoing chemotherapy found that they were able

to use the PAIS to predict those patients who had "dropped out" of treatment. Those patients who had "dropped out" of chemotherapy were found to have more adjustment problems that those patients who complete their treatment controlling for severity of disease and social background.

The PAIS has been validated with the partners of cancer patients. Goldberg et al. [1984] used the PAIS with lung cancer patients and their spouses to highlight the importance of screening spouses of cancer patients for "psychosocial impairment". These researchers conclude that "spouses of lung cancer patients deserve a psychosocial assessment as a routine element of cancer care"(p79). Baider et al. [1989] reached similar conclusions using the PAIS in a study of 39 couples in which one partner had colon cancer.

The PAIS therefore is a well validated and reliable assessment scale. It has been shown to be acceptable both to cancer patients and their partners in assessing the impact of illness and its treatment on various areas of their lives. The available norms and the body of literature in existence demonstrated that it is an appropriate tool for use with both lung cancer patients and their "primary carers".

5. The Eysenck Personality Inventory (EPI), [Eysenck and Eysenck, 1964]

The EPI is an extremely well validated measure of personality. It consists of 57 questions regarding the way in which the subject "behaves, feels and acts" after each question the subject is instructed to answer either "yes" or "no" indicating their usual way of acting or feeling by placing a cross in the appropriate yes/no circle. The scale takes approximately 5-10 minutes to complete. The EPI gives a measure of "extraversion", "neuroticism" and a "lie" scale in order to detect those individuals demonstrating a "desirability response set".

The EPI is perhaps one of the best researched assessment scales in British psychology. The scale was constructed following interviews with some 30,000 people in order to refine the questions and subject the results to a factor analysis. The test-retest reliability of the scale are quite satisfactory, Eysenck and Eysenck [1964] found that they were between +0.84 and +0.94 over a nine month period. There are parallel forms of the test and the test-retest reliability of these ranged from +0.80 to +0.95 again an acceptable finding. In reporting the results of factor analysis of the scale Eysenck and Eysenck [1964] state that the data clearly shows the presence of two orthoganol factors.

Eysenck [1962 and 1963] has demonstrated the validity of the EPI by comparing the results of the scale with the judgement of expert raters. From the studies he concludes that the

questionnaire gives an accurate and valid picture of the subject's habitual behaviour patterns.

The normative sample for the EPI was 2,000 respondents from a variety of social classes and age groups. From this sample, norms for each sub-scale were calculated and a variety of statistical manipulations conducted to examine the effects of parameters such as age and social class on the personality scores.

Eysenck, himself has used the EPI (or its forerunner the MPI) scale extensively to examine the relationship between personality and cancer proneness. Kissen and Eysenck [1962] examined 116 male lung cancer patients and 123 non-cancer controls. They found that the cancer group was considerable more extraverted than the control group and that the control group had much higher neuroticism scores than the cancer group. This result was further confirmed by Kissen [1964;1967] in lung cancer patients where he found that they had significantly lower "N" scores than did patients with other chest conditions.

The EPI, however, has been used in a number of studies to predict recovery from illness, physical complications and mood states. Glen and Cox [1968] used the EPI with 66 patients undergoing surgery for duodenal ulcer repair. Those patients with a higher "N" score experienced a more complicated recovery. Similar results have been reported by Cronin et al., [1973] with general surgery patients, Dalrymple et al. [1972]

with cholecystectomy patients and Parbrook et al. [1973] with peptic ulcer patients. In these studies neuroticism was found to correlate significantly with pain, analgesia use and complications. In the field of oncology, Hughson et al., [1988] have used the EPI to examine psychosocial morbidity resulting from mastectomy in 90 women. They found that the main predictors of morbidity at 13 months following mastectomy were high "N" scores on the EPI, age and treatment with chemotherapy. This was particularly strong in predicting anxiety and depression. Morris et al. [1977] in a study of 69 women undergoing mastectomy found that patients still distressed by mastectomy after two years had significantly higher pre-operative "N" scores than those whose distress had decreased.

The EPI therefore is a well validated and reliable scale and has been used extensively in the field of psychosocial oncology research. It has been shown to be an important predictor of reactions to stressful event and is suitable for completion by both lung cancer patients and their carers. The EPI in this study was not used as a predictor but as a possible moderating variable of psychological distress.

6. The Perceived Social Support Scale (PSSS),[Procidano and Heller, 1983]

This is a forty item self report questionnaire which measures perceived emotional social support from family and friends. The scale is described in detail in Chapter 5 and details of its scoring, psychometric properties and usage are also given. It is brief and easy to complete taking approximately 8-10

minutes. Each statement regarding emotional support is scored Yes, No or Don't know by the respondent. Scores are then summed and can be compared to the available norms. It is the most suitable tool for the assessment of perceived emotional support in cancer patients and their carers (see Appendix 2).

7. Symptoms and side effects scale.

This is a brief assessment scale designed locally in the medical oncology unit by the director of the psychosocial oncology research programme [Cull and North, 1988]. It is designed for use with lung cancer patients to assess the symptoms of the disease as well as the side effects of treatment. The scale consists of a list of symptoms and side effects and patients are instructed to rate the severity of each on the scales provided to describe how much they have been troubled by each during the past week. The scale takes approximately 2-5 minutes to complete and was easily understood in a longitudinal study of lung cancer patients conducted in the department (see Appendix 2).

8. Additional information.

In addition to the assessment scales described a range of information was recorded from the patients medical notes. This information included such items as: tumour type, treatment status, treatment regimen, time since diagnosis, performance status, and extent of disease.

The design of the study is illustrated in Figure 9.

Figure 9
The psychosocial impact of lung cancer and its treatment on patients and their primary carers: Study design.

Stage of disease	Time of assessment	Duration of assessment	Subjects	Assessment battery
First line management	Mid-point of chemo-therapy	60 mins.	Patient	Interview Schedule, HAD, PAIS, PSSS,EPI, SSE
First line management	Mid-point patients' chemo-therapy	60 mins.	Carer	Interview Schedule, HAD, GHQ,PAIS, PSSS,EPI
Follow up surveillance	Minimum of one month on follow up	60 mins	Patient	Interview Schedule, HAD, PAIS, PSSS, EPI, SSE
Follow up surveillance	Patient on follow up for one month (min)	60 mins	Carer	Interview Schedule, HAD, GHQ, PAIS, PSSS, EPI
Palliative therapy	Mid-point palliative radiotherapy	60 mins	Patient	Interview Schedule, HAD, PAIS, PSSS, EPI, SSE
Palliative therapy	Mid-point of patients' palliative radiotherapy	60 mins	Carer	Interview Schedule, HAD, GHQ, PAIS,PSSS, EPI

(Interview Schedule= Brief Interview Schedule, HAD= Hospital Anxiety and Depression Scale, GHQ= General Health Questionnaire, PAIS= Psychosocial Adjustment to Illness Scale, PSSS= Perceived Social Support from Family and Friends, EPI= Eysenck Personality Inventory, SSE= Symptoms and Side Effects Scale).

Data processing

The data from the questionnaires, the interview and the patients medical notes were collated and then entered into the departmental main frame computer system. The programme

used to perform the statistical analysis was the Statistical Package for the Social Sciences (SPSS), (Nie et al., 1975) and results were considered to be not significant where $p>0.05$.

Conclusion

This battery of scales and questionnaires has been chosen to assess, mood, adjustment to illness, personality, perceived emotional support and the number and severity of disease and the side effects of treatment. As far as possible well validated and reliable standardised assessment scale have been selected for this purpose. In addition a brief interview schedule has been designed to assess a range of demographic and attitudinal factors.

Chapter Eight

Results

The three groups of subjects (first line chemotherapy, follow-up surveillance and palliative therapy) each contained 40 patients and their "primary carers". In addition to these subjects, three others refused to take part in the study and were therefore excluded. These latter subjects were all patients receiving first line chemotherapy and their reason for refusal was that they felt too unwell to take part. As a result, these three patients and their "primary carers" were not approached subsequently and no data from them was included in the analyses. There were no other refusals in the groups of subjects receiving follow-up surveillance and palliative therapy.

Descriptive data: patients

The ages and sex of the three groups of patients are shown in Tables 1 and 2 combined with the results of a one way analysis of variance and chi square.

Table 1: Age (years)
Analysis of variance of age in the three groups of patients: means, standard deviations and F ratio (n = 40 subjects in each group).

First line	Follow up	Palliative	F ratio	Significance
Mean (SD)	Mean (SD)	Mean (SD)		
60.30 (9.30)	57.20 (9.90)	61.90 (8.00)	3.10	$p < 0.05$
Ranges: 28-74	28-72	41-74		

The analysis of variance demonstrates a significant difference between the groups in terms of age at the 0.05 level. Further analysis of this data using Scheffe's multiple range test reveals the difference to be located between the follow-up group and the palliative group ($F = 5.39$; $df = 2,117$; $p < 0.01$).

Table 2: Sex
Sex distribution of the three main groups of patients (n = 40 subjects in each group).

Sex	First Line	Follow up	Palliative
Male	32	21	28
Female	8	19	12

The sex distribution in the follow-up group is clearly different from the distribution in the other two groups ($X^2 = 7.06$; $df = 4$; $p<.02$). The ratio of males to females is almost 1:1, compared to 4:1 in the first line group and 2.3:1 in the palliative group. The implications of this sex ratio variation will be considered further later in this chapter.

The majority of patients in the three groups were married, with only a small number being separated, divorced or single (Table 3). There were no statistically significant differences between the groups in terms of marital status ($X^2= 3.08$, $df = 4$, N.S.).In addition, surprisingly few of the patients lived alone, two in the first line group, one in the follow-up group and three in the palliative therapy group.

Table 3
Marital Status of each three groups of patients (n = 40 subjects in each group).

Marital Status	First Line	Follow up	Palliative
Married	35	36	33
Sep/Div	3	1	5
Widowed	0	0	0
Single	2	3	2

(Sep/Div= separated or divorced)

The social class of subjects in the study was coded from their occupations using the Office of Population, Consenses and Surveys (1980) classification of occupations. This divides social class into five subdivisions (1-5, from (1) Professional to (5) Unskilled). No statistically significant difference was observed between the three groups in terms of the social class distribution (X^2=13.80, df =8, N.S.).

Table 4: Social Class
Distribution of the three groups of patients with that of the carer in brackets (n = 40 subjects in each group).

Social Class	First Line	Follow up	Palliative
Professional	3 (4)	0 (0)	1 (1)
Intermediate	10 (11)	6 (7)	5 (7)
Skilled	15 (13)	10 (10)	16 (14)
Semi-skilled	8 (8)	16 (15)	12 (13)
Unskilled	4 (4)	8 (8)	6 (5)

The diagnosis of lung cancer has been divided into small cell lung cancer and non small cell lung cancer (Table 5). The ratios of each are almost identical across the three groups (X^2 =0.20; df =2; N.S.).

Table 5
Diagnostic categories of the three groups of patients (n = 40 subjects in each group).

Cell Type	First Line	Follow up	Palliative
Non-small cell	22	21	20
Small cell	18	19	20

(Non-small cell = non small cell lung cancer
Small cell = small cell lung cancer)

The first line treatment that patients received, therefore, was dictated by their diagnosis. All patients initially received some form of combination chemotherapy (Table 6) following their diagnosis and there was no statistically significant difference between the groups in terms of the drug regimen that they had received (X^2=3.83; df= 6; NS).

Table 6
Original treatment regimes received by the three groups of patients.

Treatment	First Line	Follow up	Palliative
Pl/Infn	22	21	20
MACE	13	13	9
MCVP16	4	5	2
Vind/VP16	1	1	2

(Pl/Intfn = Cisplatinum plus alpha 2b interferon;
MACE= methotrexate, adriamycin, cyclophosphamide and VP16-213;
MCVP16= methotrexate, cyclophosphamide and VP16-213;
Vind/VP16= vindesine and VP16-213)

The number of months since the patients initial diagnosis increases across the groups as the patients progress through the "process" of their illness.

Table 7
Time since diagnosis (months) of the three groups of patients.

First Line	Follow up	Palliative
Mean (S.D.)	Mean (S.D.)	Mean (S.D.)
1.1 (0.40)	5.4 (1.60)	11.6 (3.10)

Descriptive data: primary carer

The mean age of the primary carer was younger than that of the patient in all three groups, although the difference did not achieve statistical significance in any of the groups. This is explained by the relationship between them, some of the carers being the patients' offspring. Unlike the patient groups, however, the age differences between the three groups does not achieve any statistical significance using analysis of variance (Table 8).

Table 8
Analysis of variance of age (years) across the three groups of primary carers: means, standard deviations and F ratio (n = 40 subjects in each group).

First Line	Follow up	Palliative	F ratio	Significance
Mean (S.D.)	Mean (S.D.)	Mean (S.D.)		
57.40(11.90)	55.90(11.60)	58.10(12.70)	0.40	N.S.

The sex distribution in the three groups of carers mirrors that seen in the patients (Table 9). The follow-up group shows a similar ratio of males to females to that observed in the patients and is significantly different from the distribution found in the first line and palliative therapy groups (X^2 = 8.40; df=2; $p < 0.02$).

Table 9
Sex distribution in the three groups of carers (n = 40 subjects in each group).

Sex	First Line	Follow up	Palliative
Male	8	20	12
Female	32	20	28

The marital status (Table 10) of the carers is also similar to that of the patients, as would be expected with no statistically significant differences between the groups (X^2=1.67; df=4; N.S.). There were only a small number of carers living alone, two in the first line group, one in the follow-up group and one in the palliative group.

Table 10
Marital status of the three groups of carers (n = 40 subjects in each group).

Marital Status	First Line	Follow up	Palliative
Married	38	36	38
Sep/Div	0	0	0
Widowed	1	1	1
Single	1	3	1

(Sep/Div= separated or divorced)

The social class of carers is very similar to that of all patients, the differences occurring when the carer is an offspring or a sibling of the patient (Table 4). There was no statistically significant difference in the distribution of social class between the three groups of carers (X^2=10.88; df=8; N.S.) or between the three groups of patients and carers (X^2=22.75; df=20; N.S.).

There was no statistically significant difference in age between male and female carers in all three groups, despite the fact

that a small number of carers were children of the patients (Table 11). Overall, there were no statistical differences between the three groups in terms of the relationship with the carer to the patient (X^2=5.00; df=8; N.S.).

Table 11
Relationship of the primary carer to the patient.

Relationship	First Line	Follow up	Palliative
Spouse	35	36	33
Brother	0	2	1
Sister	0	0	1
Son	1	0	2
Daughter	2	1	2
Friend	2	1	1

Mood: patient

The mood state of patients and their primary carers was assessed using the Hospital Anxiety and Depression Scale [Zigmond and Snaith, 1983]. This scale assesses both anxiety and depression experienced during the previous week. The mean anxiety scores in each group of patients are shown in Table 12.

Table 12
Analysis of variance of HAD (Anxiety) scores for patients in each treatment group: means, standard deviation and F ratio (n= 40 subjects in each group).

First Line	Follow up	Palliative	F ratio	Significance
5.63 (4.85)	6.90 (5.23)	6.30 (4.16)	0.70	p= 0.49 (N.S.)

The differences in mean anxiety levels between the three groups does not achieve statistical significance using an

analysis of variance (p= 20.49). The scores of the Hospital Anxiety and Depression Scale (HAD) can be used to indicate "caseness". The authors, Zigmond and Snaith have devised "cut-off" scores dividing the scale into, normal (0-7), borderline (8-10) and "case" level (11-21). Table 13, below, shows the scores of patients on the anxiety subscale of the HAD, using the cut-off scores recommended by the authors [Zigmond and Snaith, 1983]. A chi square analysis reveals that there is no significant difference between the three groups, although there is a trend for more patients in the follow up group to score in the "case" level range(X^2= 3.06; df= 4; NS).

Table 13
HAD (Anxiety) scores using cut-off scores recommended by the authors (n = 40 subjects in each group).

HAD Score	First Line	Follow up	Palliative
	n (%)	n (%)	n (%)
0-7	23 (57.5)	23 (57.5)	21 (52.5)
8-10	11 (27.5)	8 (20.0)	14 (35.0)
11-21	6 (15.0)	9 (22.5)	5 (12.5)

(0-7 = normal, 8-10 = borderline, 11-21 = "case" level)

The mean depression scores in each group of patients is shown in Table 14 below. The differences between the means across the groups of patients did not achieve statistical significance using an analysis of variance (p= 0.20).

Table 14
Analysis of variance of HAD (Depression) scores for patients in each treatment group: means, standard deviations and F ratio (n = 40 subjects in each group).

First Line	Follow up	Palliative	F ratio	Significance
3.92 (3.76)	5.37 (4.79)	4.03 (3.39)	1.62	p=0.20 (NS)

This data can also be represented using cut-off scores recommended by the authors, normal (0-7), borderline (8-10) and "case" level (11-21). The patients' scores on the depression subscale of the HAD are shown in this way in Table 15. A chi square analysis reveals no statistically significant difference between the three groups in terms of the distribution of patients' scoring in each category ($X^2=7.09$; df=4; N.S.).

Table 15
HAD (Depression) scores using cut-off scores recommended by the authors (n = 40 subjects in each group).

HAD Score	First Line	Follow up	Palliative
	n (%)	n (%)	n (%)
0-7	32 (80.00)	24 (60.00)	33 (82.50)
8-10	5 (12.50)	7 (17.50)	6 (15.00)
11-21	3 (7.50)	7 (17.50)	1 (2.5)

(0-7 = normal, 8-10 = borderline, 11-21 = "case" level)

Mood: primary carer

The primary carer also completed the HAD scale and in addition the General Health Questionnaire, 28 item version (GHQ) [Goldberg and Hillier, 1979]. Table 16 shows the mean HAD (Anxiety) scores for each group of carers. Analysis of

variance revealed no statistically significant difference between the three groups (p = 0.70).

Table 16
Analysis of variance of HAD (Anxiety) scores of primary carers in each group: means, standard deviations and F ratio (n=40 subjects in each group).

First Line	Follow up	Palliative	F ratio	Significance
10.52 (5.49)	9.93 (5.50)	9.48 (5.69)	0.36	p=0.70 (N.S.)

There is a marked similarity in mean scores between the three groups of carers. When the data is analysed using cut-off scores recommended by the authors, the number scoring in the "case" level range is extremely high, as shown in Table 17. A chi square analysis reveals that there is no statistically significant difference between the distribution of carers scoring in each category across the three groups ($X^2=5.62$; df=4; N.S.).

Table 17
HAD (Anxiety) score of primary carers using cut-off scores recommended by the authors (n = 40 subjects in each group).

HAD Score Anxiety	First Line n (%)	Follow up n (%)	Palliative n (%)
0-7	10 (25.00)	12 (30.00)	14 (35.00)
8-10	5 (12.50)	11 (27.50)	5 (12.50)
11-21	25 (62.50)	17 (42.50)	21 (52.50)

(0-7 = normal, 8-10 = borderline, 11-21 = "case" level)

A comparison between the number of patients and carers whose HAD (Anxiety) scores fall into each category, using cut-

off scores, reveals a striking difference between the two as shown in Table 18.

Table 18
HAD (Anxiety) scores for patients and their "primary carers" using cut-off scores recommended by the authors (n = 40 subjects in each group).

	First Line		Follow up		Palliative	
HAD score	patient	carer	patient	carer	patient	carer
Anxiety	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
0-7	23 (57.5)	10 (25.0)	23 (57.5)	12 (30.0)	21 (52.5)	14(35.0)
8-10	11 (27.5)	5 (12.5)	8 (20.0)	11 (27.5)	14 (35.0)	5 (12.5)
11-21	6 (15.0)	25 (62.5)	9 (22.5)	17 (42.5)	5 (12.5)	21 (52.5)

(0-7 = normal range, 8-10 = borderline range, 11-21 "case" level)

The number of carers whose scores fall within the "case" level of anxiety is significantly higher than the number of patients' scores falling within this category. This effect is maintained across the three treatment groups but is at its most profound during first line chemotherapy (X^2= 19.02; df= 2; $p<0.001$) and during palliative radiotherapy (X^2=15.51; df=2; $p<0.001$). The period during which the patient is not receiving any treatment but is returning to the hospital for follow-up surveillance is still very stressful for both patients and their carers. Although the number of carers scoring in the "case" level range is slightly less in this group than the other two, the number of patients scoring in this range has risen. The difference between the distribution of the two still achieves statistical significance (X^2= 6.39; df= 2; $p<0.05$).

The mean HAD (depression) scores for each group of primary carers is shown in Table 19. Analysis of variance across the mean scores of the three groups does not achieve statistical significance (p = 0.36).

Table 19
Analysis of variance of HAD (Depression) scores of primary carers in each group: means, standard deviations and F ratio (n = 40 subjects in each group).

First Line	Follow up	Palliative	F ratio	Significance
6.15 (4.83)	4.60 (4.51)	5.70 (5.52)	1.03	p=0.361(N.S.)

This data is shown in Table 20 using cut-off scores recommended by the authors. A chi square analysis of the distribution of scores between the three groups fails to achieve statistical significance (X^2= 7.30; df= 4; NS).

Table 20
HAD (Depression) scores of primary carers using cut off scores recommended by the authors (n= 40 subjects in each group).

HAD score	First Line	Follow up	Palliative
Depression	n(%)	n(%)	n(%)
0 - 7	22 (55.0)	30 (75.0)	27 (67.5)
8 - 10	10 (25.0)	4 (10.0)	3 (7.5)
11 - 21	8 (20.0)	6 (15.0)	10 (25.0)

(0-7 = normal range, 8-10 = borderline range, 11-21 "case" level)

In comparing the HAD depression scores of patients and their primary carers (Table 21), the effect is less dramatic than the HAD anxiety scores. The results suggest that depression is less

of a problem for both patients and carers than anxiety. It is noticeable, however, that the number of carers experiencing "case" levels of depression during palliative therapy is significantly greater than the number of patients in this group scoring in the same category (X^2= 8.96; df=2; p<0.02). Comparison of the numbers of patients and carers scoring in each category in the first line group (X^2= 5.79; df= 2; NS) and the follow up group (X^2= 1.81; df= 2; NS) fail to achieve statistical significance.

Table 21
HAD (depression) scores for patients and their "primary carers" using cut off scores recommended by the authors (n= 40 subjects in each group).

	First Line		Follow up		Palliative	
HAD score	patient	carer	patient	carer	patient	carer
depression	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
0-7	32 (80.0)	22 (55.0)	26 (65.0)	30 (75.0)	33 (82.5)	27 (67.5)
8-10	5 (12.5)	10 (25.0)	7 (17.5)	4 (10.0)	6 (15.0)	3 (7.5)
11-21	3 (7.5)	8 (20.0)	7 (17.5)	6 (15.0)	1 (2.5)	10 (25.0)

(0-7 = normal range, 8-10 = borderline range, 11-21 "case" level)

A surprising finding from the Table 21 is the small number of patients receiving palliative therapy who score in the "case" level range for depression on the HAD. This finding can be explained in a later section looking at the patients' perceptions of the aims of treatment.

In addition to the Hospital Anxiety and Depression Scale, carers also completed the GHQ (28 item) scale [Goldberg and

Hillier, 1978]. This scale can be used as a screening tool to assess "probable caseness" as well as providing information on four subscales (described previously).

Table 22 shows the mean GHQ scores for each group of carers on the four subscales of the test.

Table 22
Analysis of variance of GHQ scores for each group of carers on each subscale: means, standard deviation and F ratio (n=40 subjects in each group).

GHQ	First Line	Follow up	Palliative	F ratio	Significance
Somatic symptoms	1.90(1.50)	0.90(1.00)	1.50(1.10)	5.90	p=0.004
Anxiety and insomnia	3.28(1.80)	2.20(1.30)	1.80(1.20)	11.27	p<0.001
Social dysfunction	1.83(1.60)	0.80(0.80)	0.90(0.80)	8.31	p<0.001
Severe depression	1.20(0.90)	1.00(1.00)	1.00(0.90)	0.46	p=0.63 (N.S.)
Total score	8.00(4.90)	4.90(3.20)	5.20(3.10)	8.32	p<0.0001

An analysis of variance performed between the three groups found significant differences on three out of the four subscales and with respect to the GHQ total score. There was a significant difference between the groups of carers in the "somatic symptoms" subscale ($p = 0.004$). Further analysis of this difference using Scheffe's multiple range test revealed the difference to be between the first line management group and the follow-up group ($F = 11.42$; $df = 2, 117$; $p < 0.001$) and between the follow-up group and the palliative therapy group ($F = 4.94$; $df = 2, 117$; $p < 0.01$) thus suggesting that the carers of patients who were receiving first line chemotherapy or palliative therapy experienced more severe somatic

symptomatology than the carers of patients in the follow-up group. These somatic symptoms include, "feeling run down" and "out of sorts", "feeling ill", experiencing pains and "tightness in the head" and experiencing "hot and cold spells".

The difference between the groups on the "anxiety and insomnia" subscale was also significant ($p < 0.0001$). Further analysis using Scheffe's multiple range test revealed the differences to lie between the first line group and the follow-up group ($F = 11.00$; $df = 2, 117$; $p < 0.001$) and the first line group and the palliative therapy group ($F = 21.14$; $df = 2, 117$; $p < 0.001$) thus indicating that the carers of patients receiving first line chemotherapy experience a greater severity of symptoms of anxiety and insomnia than the other two groups. These symptoms include; "losing sleep over worry", "difficulty staying asleep", "feeling edgy and bad tempered", "feeling scared and panicky", "finding everything getting on top of oneself" and "feeling nervous and strung up".

The difference between the groups on the "social dysfunction" subscale also reached statistical significance using analysis of variance ($p < 0.0001$). Scheffe's multiple range test revealed the difference to lie between the carers in the first line group and the follow-up group ($F = 13.78$: $df = 2, 117$; $p < 0.001$) and between the first line group and the palliative therapy group ($F = 11.03$; $df = 2,117$; $p < 0.001$) thus indicating that the greatest degree of social dysfunction is found in carers of patients receiving first line chemotherapy. This includes difficulties in "keeping oneself busy and occupied", "taking

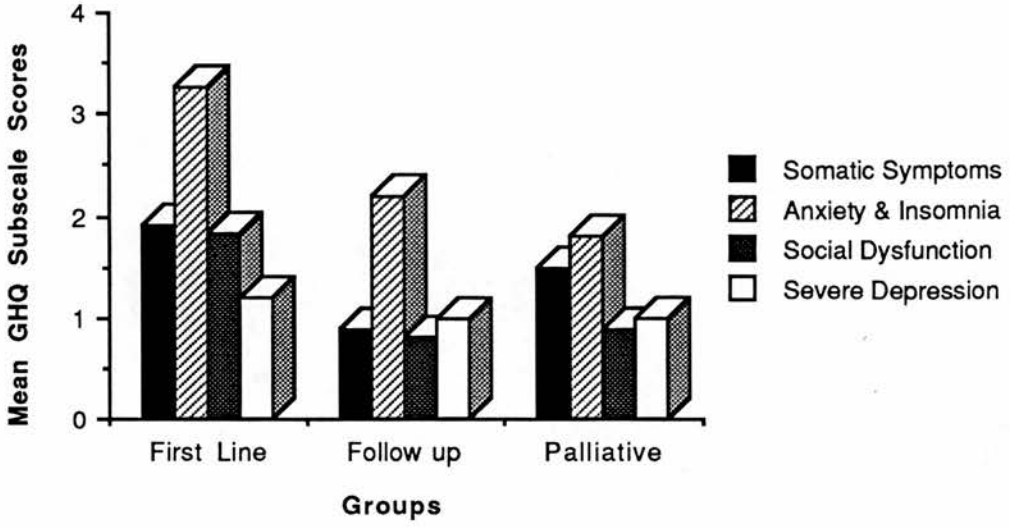
longer to do things", "finding it difficult to perform tasks well", "not feeling as though one is playing a useful part in things" and "feeling incapable of making decisions".

Analysis of variance across the three groups on the fourth subscale of the GHQ (severe depression) did not achieve statistical significance ($p = 0.63$) indicating that the groups were similar in terms of the degree of depression experienced by the carers in each group.

The analysis of variance across the three groups of the GHQ, total score revealed a significant difference ($p < 0.0001$). Further analysis of these differences using Scheffe's multiple range test revealed the difference to lie between the first line group and the follow-up group ($F = 13.50$; $df = 2, 117$; $p < 0.001$) and between the first line group and the palliative therapy group ($F = 11.44$; $df = 2, 117$; $p < 0.001$) thus indicating that the greatest level of distress lay in the carers of patients receiving first line chemotherapy. It is also of importance to note that the mean total scores for each group (8.00, 4.90 and 5.20) all lie within the range indicating "probable psychiatric caseness", the "cutting" score being 4/5.

The data concerning the four subscales of the GHQ is illustrated in Graph 1, where the trend towards a reduction in mean GHQ scores across the three groups can be clearly seen.

Graph 1. GHQ subscale scores for each group of carers.



Data concerned with the GHQ total scores is shown below in a different form (Table 23). The scores for each group are divided into subjects scoring within "normal" range (0-4) and those scoring above the threshold indicative of "psychiatric caseness" (5 or more).

Table 23
General Health Questionnaire total scores using the cut off points recommended by the authors (n=40 subjects in each group).

	First Line		Follow up		Palliative	
GHQ score	n	(%)	n	(%)	n	(%)
0 - 4	11	27.5	20	50.0	13	32.5
5 +	29	72.5	20	50.0	27	67.5

(Normal range 0-4; possible "caseness" 5+)

This latter data demonstrate the extremely high levels of distress found in the carers of patients with lung cancer. A chi square analysis, however, reveals that there is no significant difference between the three groups in terms of the number of carers scoring in the "case" level range in each (X^2= 4.80; df=

2; NS). The number of subjects scoring at "case level" is higher using this form of the GHQ than on the HAD. This is probably due to the different time scales with which the two questionnaires are concerned and the fact that the questions are assessing different specific functions.

The relationship between the mood state of patients and their "primary carer".

Anxiety

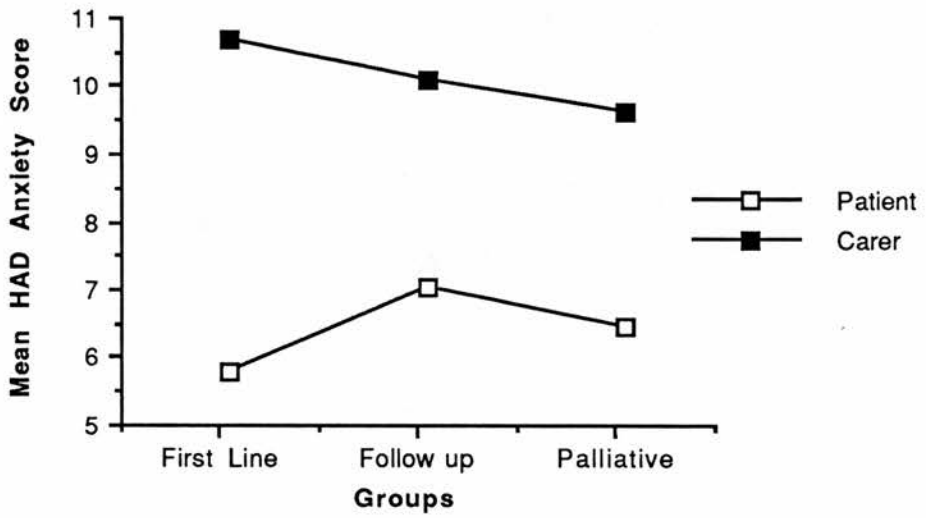
The scores of patients and their primary carers on the anxiety subscale of the HAD scale are significantly different in all three groups. These results are shown in Table 24 and illustrated in Graph 2 where the scale of difference can be fully appreciated.

Table 24
A comparison of HAD anxiety scores of patients and their primary carers: means, standard deviations and t-test results (n=40 subjects in each group).

	Patient	Carer			
Man. Stage	Mean (SD)	Mean (SD)	DF	t	Significance
First Line	5.63 (4.85)	10.52 (5.49)	76	-4.23	p<0.0001
Follow up	6.90 (5.23)	9.93 (5.50)	77	-2.52	p<0.01
Palliative	6.30 (4.16)	9.48 (5.69)	71	-2.85	p<0.005

(Man.Stage= stage of management)

Graph 2. HAD Anxiety: Patient and Carer.



Despite these statistical differences, however, the anxiety scores for patients and their primary carers in the first line management group were found to be significantly correlated ($r = .450$; $p < 0.01$), as were those in the follow-up group ($r = .375$; $p < 0.05$). The anxiety scores of patients and their carers in the palliative therapy group, however, just failed to achieve statistical significance ($r = .273$; N.S.) (Table 25). These results indicate that an association exists between the level of anxiety in patients and the level of anxiety in those who care for them.

Table 25
Comparative psychological status of patients and their carer (Anxiety:HAD) (n= 40 pairs in each group).

Management Stage	Patient (mean)	Carer (mean)	Correlation r	Significance p
First Line	5.63	10.52	0.450	p < .01
Follow up	6.90	9.93	0.375	p < .05
Palliative	6.30	9.48	0.273	N.S.

Depression

The pattern of test scores with respect to depression is different to that of anxiety (Table 26). The difference in HAD depression scores between patients and their primary carers achieves statistical significance in the first line management group, but fails to do so in the follow-up and palliative therapy groups. The relationship between the HAD depression scores of the patients and their carer is illustrated in Graph 3. The scores in the first line and palliative groups are higher for the carer than for the patient but this effect is reversed in the follow up group. Despite the fact that only the difference in the first line group is statistically significant, the trends are interesting. Patients in the follow up group tend to be more depressed than the other two groups. This could be due to the uncertainty that the patient is faced with at this time and perhaps a sense of relief or hopelessness in the carer as treatment has ceased.

Table 26
A comparison of HAD depression scores of patients and their primary carers: means, standard deviations and t-test results (n = 40 subjects in each group).

	Patient	Carer			
Man.Stage	Mean (SD)	Mean (SD)	DF	t	Significance
First Line	3.92 (3.76)	6.15 (4.83)	73	-2.30	$p < 0.02$
Follow up	5.37 (4.79)	4.60 (4.51)	77	0.75	$p = 0.46$
Palliative	4.03 (3.39)	5.70 (5.52)	64	-1.64	$p = 0.11$

(Man.Stage = Stage of Management)

Correlation coefficients between HAD depression scores of patients and their primary carers failed to achieve statistical significance (first line management r = .188; follow-up r = -.075; palliative therapy r = 0.131) (Table 27).

Graph 3. HAD Depression: Patient and Carer.

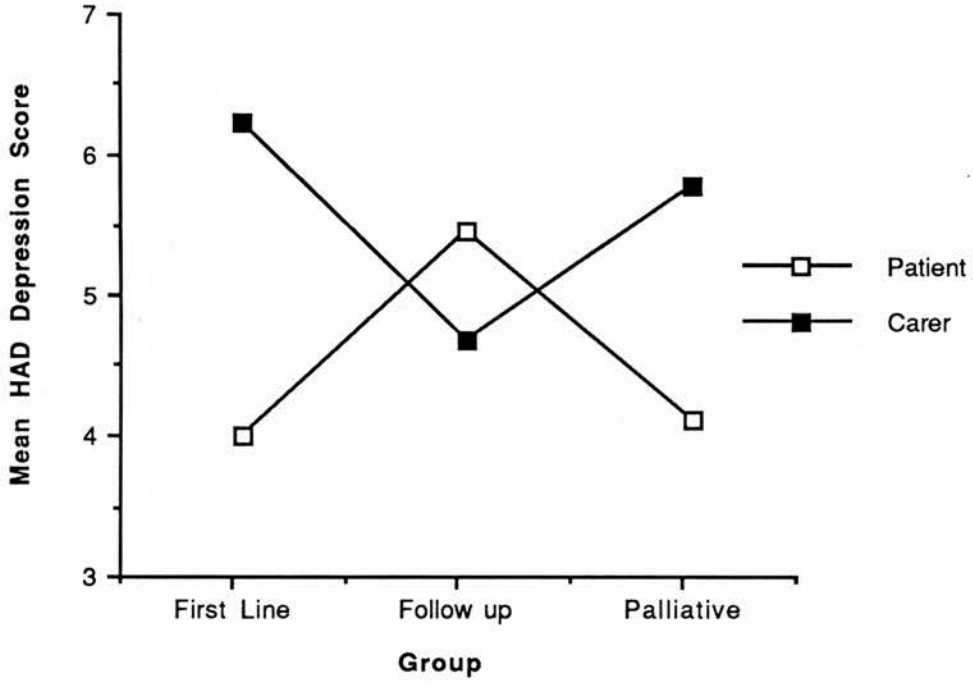


Table 27
Comparative psychological status of patients and their carers (Depression: HAD) (n = 40 pairs in each group).

Management Stage	Patient (mean)	Carer (mean)	Correlation r	Significance p
First Line	3.92	6.15	0.188	N.S.
Follow up	5.37	4.60	-0.075	N.S.
Palliative	4.03	5.70	0.131	N.S.

(r= Pearson correlation)

The impact of the patients' mood state on that of the carer is further borne out by examining the correlation of the patients'

HAD scores with the anxiety and depression subscales of the General Health Questionnaire (GHQ) which was completed by the carer only. In the first line management group the correlation between the patients' HAD anxiety score and the carers' GHQ, anxiety subscale score, was statistically significant ($r = .339$, $p < .05$). This trend was continued in the follow-up group ($r = .399$, $p < .02$) and in the palliative therapy group ($r = .354$, $p < .05$). This latter correlation, unlike the correlation found between the patients' HAD anxiety score and that of the carers does achieve statistical significance.

In interpreting this data one must consider that the relative time periods for the HAD scale and the GHQ are at variance with each other. The GHQ is concerned with the "past few weeks" whereas the HAD scale is concerned specifically with the last week. The data from the current study suggests that the distress in the primary carer is an enduring phenomenon rather than a short term one.

The correlation coefficients between HAD depression scores and the GHQ depression subscale accord with the earlier correlation coefficients of the HAD depression scores of patients and their carers, in that none of them achieved statistical significance.

Correlation coefficients, however, between the carers' anxiety and depression scores measured by the HAD and the GHQ subscales were all highly significant ($p < .001$) as would be expected.

Mood: sex differences

The sex distribution of the three groups was described earlier in this chapter. The follow-up group of patients and their primary carers had a male to female ratio that was clearly different to that found in the other two groups. The implications of any sex differences in mood state was, therefore, an important question to be investigated. This was examined in both patients and their primary carers in all three groups for both anxiety and depression scores of the HAD and the subscale scores (somatic symptoms, anxiety, social dysfunction and depression) of the GHQ.

In the three groups of patients there was no statistically significant difference between the scores for anxiety and depression of the HAD questionnaire, between males and females. Amongst the three groups of primary carers there was no statistically significant difference between the GHQ subscale scores of males and females. The scores of the anxiety and depression subscales of the HAD questionnaire were not significantly different in the first line management group and in the follow-up group. In the carers of those patients receiving palliative therapy, however, the mean anxiety score for females was significantly higher than for males (Table 28).

Table 28
HAD anxiety scores of primary carers of patients receiving palliative therapy: males versus females. (Means, standard deviations and t-test results.)

Sex	N	Mean (S.D.)	D.F.	t	Significance
Male	12	6.50 (5.90)	18	-2.17	p = 0.04
Female	28	10.80(5.20)			

The scores for the depression subscale of the HAD between males and females in this group of primary carers did not achieve statistical significance.

There appears, therefore, to be no consistent effect of sex on mood state on patients and their primary carers across the three groups. The female carers in the palliative therapy group have a mean age of 59.0 years (SD = 11.9). The aim of palliative therapy is to alleviate troublesome symptoms rather than to prolong life. This group of women who are all "spouses" might be preparing for the impending death of their husbands and this heightened anxiety could be conceptualised as a from of "anticipatory grief".

The relationship of other significant factors to the mood state of patients and their primary carers

Demographic data: patients

A range of demographic data was collected on patients and their primary carers and their relationship to mood state was examined.

In the three groups of patients no significant associations were found between anxiety and depression as assessed by the HAD questionnaire and the following variables: the patients' age; marital status (married versus not married); employment (working versus not working); and knowing someone close to them who had previously been treated for cancer. Those patients who had previous treatment for anxiety/depression (8 in the first line group, 6 in the follow-up group and 6 in the palliative group) were not significantly more anxious or depressed than those without such a history.

Similarly, no significant associations were found between demographic variables of the primary carer and the patients' HAD scores (anxiety and depression) across the three groups. These variables included the age of the primary carer, the employment status of the primary carer (working versus not working) and having someone close to them treated for cancer in the past. Finally, there was no statistically significant differences in age between male and female patients in the three groups.

Demographic data: primary carer

No significant associations were found between the age of the primary carer, their employment status (working versus not working) and knowing someone close to them treated for cancer in the past and their mood state. This lack of association was maintained across all three groups of carers and also between the aforementioned variables, the anxiety and depression subscales of the HAD questionnaire and the subscales of the GHQ. (In the three groups of carers there were no statistically significant differences between male and female carers with respect to age.)

Similarly, no significant associations were found between the demographic variables in the patient: age; marital status (married versus not married); employment (working versus not working); and knowing someone close to them in the past treated for cancer and the anxiety and depression subscales of the HAD and the subscales of the GHQ of the carer. There was no difference in mood state between those carers previously treated for anxiety and depression (10 in the first line group, 8 in the follow-up group and 11 in the palliative group) and those without such a history. This suggests that previous treatment for emotional problems did not predispose this group towards greater levels of distress. This data suggest that certain demographic variables from both the patient and their carer were not significantly correlated with their mood state. This result was maintained in both patients and carers, irrespective of the stage of their disease "process".

Illness and treatment variables: patient

The contributions of a number of variables related to the patients' illness on mood state (anxiety and depression) were assessed across the three groups of patients. In the first line management group and the follow-up group no significant correlations were found between the number of symptoms and side effects, the severity of these symptoms and side effects, performance status and time since diagnosis (months) and anxiety and depression. In the palliative therapy group, however, the correlation between the number of symptoms and side effects and anxiety ($r = .364$) achieved statistical significance ($p < .05$). The correlation between these variables and depression failed to achieve statistical significance. The severity of the side effects, performance status and time since diagnosis also failed to achieve statistical significance.

This suggests that the effect of symptomatology as assessed both by the patient and the physician on mood state is relatively weak throughout the course of the illness. During palliative therapy, however, those patients who have more symptoms tend to be more anxious. This could be related to the type of symptoms experienced by the patient as in this group, 32 out of the 40 patients (80 per cent) experienced both pain and breathlessness.

This association between physical symptoms and mood state has been reported elsewhere [Goldberg, et al. 1984]. The relationship is clearly not related solely to the stage of the

disease because the levels of anxiety across the three groups of patients do not differ significantly as has been discussed earlier.

Finally, neither the type of lung cancer (non small cell lung cancer versus small cell lung cancer) nor the chemotherapy combination given during first line management had any significant effect on the patients' anxiety and depression scores of the HAD questionnaire across all three groups. Table 29 shows the distribution of type of lung cancer across the three groups.

Table 29
Type of lung cancer by stage of management (n = 40 subjects in each group).

Cell Type	First Line		Follow up		Palliative	
	n	(%)	n	(%)	n	(%)
Non-small cell	22	(55)	21	(52.5)	20	(50)
Small cell	18	(45)	19	(47.5)	20	(50)

(Non-small cell= non small lung cancer
Small cell = small cell lung cancer)

Illness and treatment variables: primary carer

The contributions of variables from the patients' illness to the mood state of the primary carer were examined. No significant correlations were found between the performance status of the patient, the symptoms and side effects experienced by the patient, the severity of the side effects, time since diagnosis and the mood state of the primary carers in all three groups. Correlations were performed between

these illness variables and the anxiety and depression subscales of the HAD questionnaire and the subscales of the GHQ. No significant associations were found.

The mood state of the primary carer was examined in relation to the type of lung cancer from which the patient was suffering. In those carers of patients receiving first line chemotherapy and those receiving palliative therapy there was no significant difference in levels of anxiety and depression in the different diagnostic groups (cell type) as assessed by the HAD questionnaire.

In the carers of patients receiving follow-up observation the mean anxiety level of carers of patients with non small cell lung cancer (12.24; SD = 4.37) was significantly higher than the mean anxiety level of carers of patients with small cell lung cancer (7.37; SD = 5.59). This difference was found to be highly significant ($t = 3.05$; $p = .004$).

This effect was maintained for mean depression scores as well. The mean depression score for carers of patients with non small cell lung cancer (6.29; SD = 4.92) was significantly higher than the mean depression score of carers of patients with small cell lung cancer (2.74; SD = 3.18). Again this difference was highly significant ($t = 2.73$; $p = .009$).

The reason for this effect is not immediately obvious from the data. There is no significant difference between the two

diagnostic groups of the follow-up group in terms of performance status, the number of symptoms reported by the patient and the severity of these symptoms. One could postulate that there was a difference between the two groups of patients during their first line chemotherapy in terms of performance status, the number of symptoms and side effects and the severity of those symptoms and side effects and that this has lead to persistently raised anxiety and depression levels. From this data we have no way of knowing for certain.

Table 30, shows that there is a statistically significant difference across the three groups of patients in terms of the number of symptoms and side effects and that performance status deteriorated over time.

Table 30
Analysis of variance of illness variables across the three groups of patients. (Means, standard deviations, F-ratios and significance.) (n = 40 subjects in each group.)

	First Line	Follow up	Palliative	F-ratio	Significance
Illness variable	Mean (S.D.)	Mean (S.D.)	Mean (S.D.)		
SSE (number)	4.4 (2.4)	0.7 (0.9)	4.4 (2.0)	51.47	p<0.0001
SSE (severity)	12.0 (6.5)	1.6 (2.0)	12.7 (6.6)	52.11	p<0.0001
P.S.	0.63(0.49)	0.25 (0.43)	1.82(0.54)	110.57	p<0.0001

(SSE (number) = the number of symptoms and side effects;
SSE (severity) = the severity of these side effects;
P.S. = Performance Status)

A Scheffe's multiple range test performed between the three groups of patients with respect to the number of symptoms and side effects reveals that the differences between the first line group and the follow-up group ($F = 76.69$; $df = 2, 117$; $p <$

0.001) are highly significant. The same pattern is observed using Scheffe's test with the severity of these symptoms and side effects (first line versus follow-up $F = 72.80$; $df = 2, 117$; $p < 0.001$ follow-up versus palliative $F = 83.25$; $df = 2, 117$; $p < 0.001$). A Scheffe's test between the three groups with respect to performance status reveals significant differences between them (first line versus follow-up $F = 11.48$; $df = 2, 117$; $p < 0.001$, first line versus palliative $F = 117.55$; $df = 2, 117$; $p < 0.001$, follow-up versus palliative $F = 202.50$; $df = 2, 117$; $p < 0.001$).

In examining the first line management group, however, there is no statistically significant difference between those patients with non small cell lung cancer and those with small cell lung cancer in terms of the number of symptoms and side effects, the severity of these side effects and performance status as judged by the physicians. A tentative conclusion, therefore, is that the difference in the anxiety and depression levels of the spouse are not related to current illness variables or illness variables from their first line treatment.

One hypothesis might be that the effect was due to a specific treatment side effect. Those patients with small cell lung cancer received treatment which caused alopecia whereas those patients with non small cell lung cancer did not lose their hair. The lower level of anxiety and depression in the follow-up group may be due to the fact that, at follow-up, the patients' hair will be re-growing. This may be interpreted by the carer as a positive sign of returning health or treatment

success and therefore lead to a reduction of anxiety and depression scores in this group. In the context of this study however, this remains conjecture as the data to substantiate it have not been collected.

The different combinations of chemotherapy given during the patients' first line management was not found to have a statistically significant impact on the levels of anxiety and depression in the primary carer.

The illness and treatment variables assessed in this study do not have any consistent impact on the mood state of the primary carers at different stages of the illness "process". There is however, tentative evidence of the effect of the type of lung cancer on mood state although the reasons for this are unclear.

Sex differences: illness variables

The variables of performance status, the number of symptoms and side effects, the severity of these symptoms and side effects and time since diagnosis were examined in terms of male versus female. In the three groups of patients there was no statistically significant difference between males and females in any of these variables.

Personality variables

The Eysenck Personality Inventory (EPI) assesses the personality traits of extraversion and neuroticism. The extraversion and neuroticism scores are shown in Table 31.

Table 31
Analysis of variance of EPI, extraversion and neuroticism scores in patients (n= 40 patients in each group).

EPI	First Line	Follow up	Palliative	F ratio	Significance
	Mean (S.D.)	Mean (S.D.)	Mean (S.D.)		
Extraversion	10.20 (3.60)	12.00 (3.50)	12.10 (3.40)	3.77	p = 0.026
Neuroticism	9.50 (3.80)	11.50 (3.60)	10.50 (2.90)	3.50	p = 0.033

The one way analysis of variance clearly shows that there is a statistically significant difference between the three groups of patients in terms of extraversion and neuroticism (The difference in extraversion scores is located between the first line group and follow-up group $F = 5.43$; $df = 2, 117$; $p < 0.01$ and the first line and palliative group $F = 5.58$; $df = 2, 117$; $p < 0.01$. The difference in neuroticism scores lies between the first line and follow-up group $F = 7.00$; $df = 2, 117$; $p < 0.01$, using Scheffe's multiple range test). The EPI measures trait characteristics and one could conclude that the three groups are therefore composed of patients of different personality types. A caveat must be applied here however when using trait measures in life threatening illness. Eysenck and Eysenck (1975) have shown that scores of neuroticism and extraversion can change markedly during episodes of severe

illness and must be treated with some caution if used to estimate these characteristics pre-morbidly. Bianchi and Ferguson (1977) have found that EPI are not only changed by illness but can also be heavily influenced by anxiety states. It can be assumed, therefore, that the pre-morbid EPI scores of the three groups would necessarily be different. This must be treated with caution, however, as the pre-morbid EPI scores were not obtained.

The EPI scores of the carers showed a similar trend in that there was a statistically significant difference between the extraversion scores of the three groups. The neuroticism scores of the three groups, however, did not achieve statistical significance (Table 32 using analysis of variance). Scheffe's multiple range test revealed the difference to lie between the first line group and the follow-up group ($F = 8.06$; $df = 2, 117$; $p < 0.001$) and between the first line group and the palliative therapy group ($F = 4.30$; $df = 2, 117$; $p < 0.025$).

Table 32
Analysis of variance of EPI extraversion and neuroticism scores in carers.

EPI	First Line	Follow up	Palliative	F ratio	Significance
	Mean (S.D.)	Mean (S.D.)	Mean (S.D.)		
Extraversion	10.60 (3.60)	12.70 (3.30)	12.10 (3.00)	4.32	p <0.01
Neuroticism	10.00 (4.00)	11.60 (3.50)	11.1 (2.80)	2.23	p=0.11 (NS)

The contribution of both patients' extraversion and neuroticism scores and those of the carers to their respective anxiety and depression scores of the HAD questionnaire proved not to be statistically significant in the three groups.

Correlations between the patients' extraversion (E) and neuroticism (N) scores and the patients' anxiety and depression scores were not significant in all three groups. The same applied to the carers' "E" and "N" scores and the patients' anxiety and depression scores across the three groups. The carers' personality scores and anxiety and depression scores in the three groups were not significantly correlated. Finally, the correlation between the patients' personality scores and the carers' anxiety and depression scores was not statistically significant.

The results consistently demonstrate that there is no statistically significant association between extraversion and neuroticism and anxiety and depression in lung cancer patients and their primary carers, irrespective of the stage in the management process that they had reached.

Sex differences: personality variables

The EPI extraversion and neuroticism score in each patients group were examined with respect to gender. In the three groups there were no statistically significant sex differences in the scores in the aforesaid traits.

In the three groups of carers, however, a statistically significant sex difference in the EPI scores was found. In the first line management group, female carers (n=32) were found to have statistically higher mean extraversion scores (11.30; SD=3.2) than the male carers' (n=8) mean extraversion score

(7.30; SD = 3.4), ($p<0.01$). The correlations with anxiety and depression, however, failed to achieve statistical significance for both male and female carers, suggesting that the EPI scores are not associated with mood state. In this group of carers there was no statistically significant difference between male and female neuroticism scores.

In the follow up group of carers there was no statistically significant difference between the extraversion and neuroticism scores of the sexes.

The carers of patients receiving palliative therapy followed a similar pattern to the first line management group. There was a statistically significant difference in the mean extraversion scores of males (n=12) versus females (n=28). The mean score of males in this group, however, was higher (13.75; SD=3.05) than that of females (11.39; SD=2.86), ($p=0.03$). Again, the correlations between anxiety and depression failed to achieve statistical significance. The neuroticism scores of males versus females failed to achieve statistical significance.

Social Support and Psychological State

The Perceived Social Support Scale (PSSS) [Procidano and Heller, 1983] is divided into two subscales: social support from the family and social support from friends.

There was no statistically significant difference between the two perceived social support scales in the three groups for

both patients and their primary carers (Table 33 and Table 34).

Table 33
Analysis of variance of perceived social support in patients (n=40 subjects in each groups).

PSS	First Line	Follow up	Palliative	F ratio	Significance
	Mean (SD)	Mean (SD)	Mean (SD)		
Family	14.70(6.20)	13.50(6.90)	13.70(6.20)	0.38	N.S.
Friends	10.00(7.40)	10.40(7.80)	11.00(7.00)	0.16	N.S.

(PSS= Source of Perceived Social Support)

Table 34
Analysis of variance of perceived social support in carers (n= 40 subjects in each group).

PSS	First Line	Follow up	Palliative	F ratio	Significance
	Mean (SD)	Mean (SD)	Mean (SD)		
Family	15.10(5.90)	13.10(6.70)	13.30(6.40)	1.2	N.S.
Friends	12.40(7.60)	1.40 (7.50)	12.50(6.50)	1.1	N.S.

(PSS= Source of Perceived Social Support)

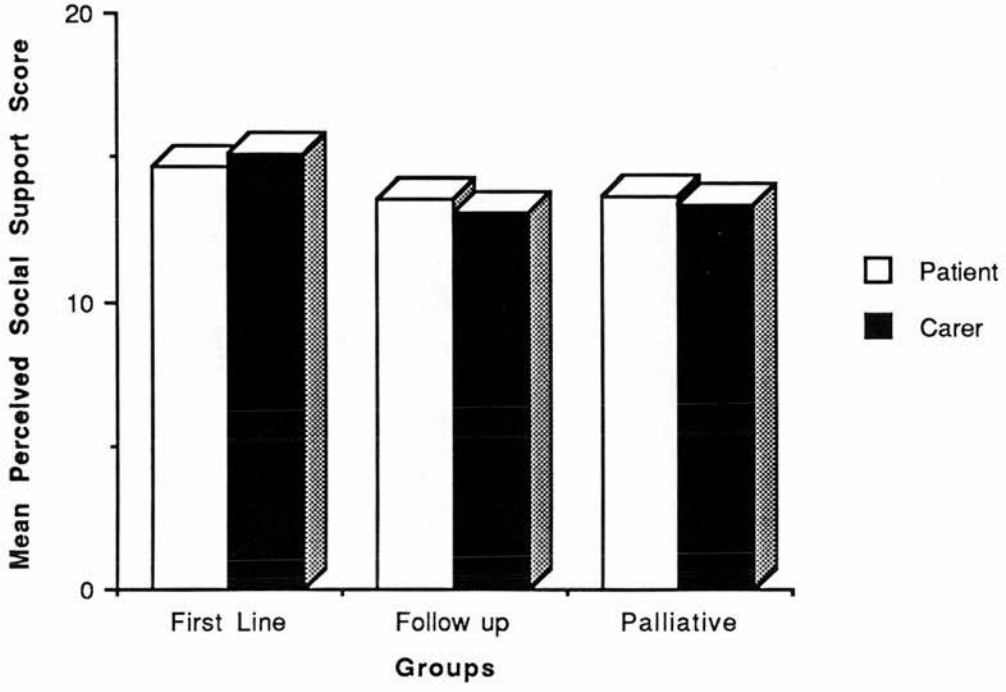
Comparisons (using T-tests) between the perceived social support scores for patients and their primary carers revealed that there were no statistically significant differences between them in the three groups. This proved to be the same when examining patients and carers social support from both family and friends. There were, however, significant correlations between perceived social support scores of patients, suggesting that if the patient has a high degree of social support, so does the carer (Table 35, and illustrated in Graphs 4 and 5).

Table 35
The relationship between perceived social support in the patients and their primary carer (n=40 subjects in each group).

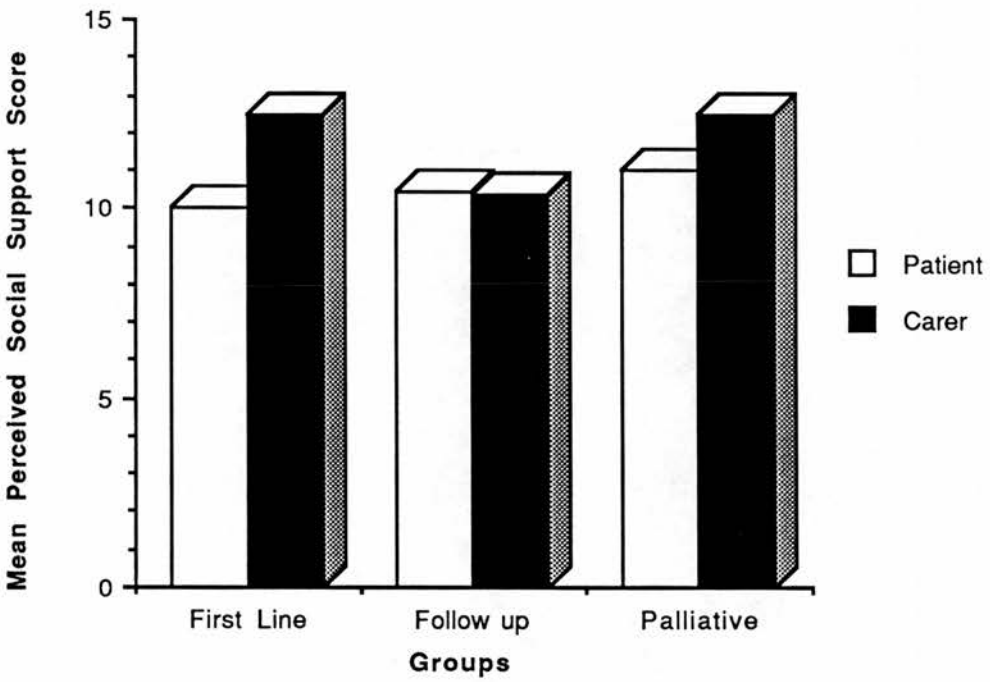
Stage	Social support	Patient	Carer	Pearson Correlation	Significance
		(Mean)	(Mean)	r	p
First Line	Family	14.70	15.13	0.704	p<0.001
First Line	Friends	10.05	12.45	0.249	N.S.
Follow up	Family	13.55	13.10	0.937	p<0.001
Follow up	Friends	10.43	10.38	0.618	p<0.001
Palliative	Family	13.68	13.35	0.917	p<0.001
Palliative	Friends	10.98	12.48	0.539	p<0.001

(Social support=perceived social support)

Graph 4.
Perceived Social Support from Family: Patient and Carer.



Graph 5.
Perceived Social Support from Friends: Patient and Carer.



The relationship between social support and mood state in both patients and their primary carers was examined. None of the correlations between social support from friends and family and anxiety and depression with respect to the patients achieved statistical significance. This pattern remained consistent irrespective of the stage of management that the patient had achieved (Table 36 and 37).

Table 36
The relationship of perceived social support to anxiety (HAD): patient.

P.S.S.	First Line	Follow Up	Palliative
	r	r	r
Family	0.248	0.029	0.285
Friends	0.078	-0.092	-0.127

(P.S.S.= perceived social support; r=Pearson Correlation)

Table 37
The relationship of perceived social support to depression (HAD): patient.

P.S.S.	First Line	Follow Up	Palliative
	r	r	r
Family	0.297	0.134	0.202
Friends	0.023	-0.011	-0.058

(P.S.S.= perceived social support; r=Pearson Correlation)

These results suggest that in terms of the patients there is no significant association between perceived emotional social support and anxiety and depression. Thus, for this group, the hypothesis that social support acts as a "buffer" against psychological distress is not supported.

The relationship between social support and distress with respect to the carer, however, is not so consistent (Tables 38 and 39).

Table 38
The relationship of perceived social support to anxiety (HAD): primary carer.

P.S.S	First Line	Follow Up	Palliative
	r	r	r
Family	0.471 **	0.143	0.306
Friends	0.177	0.212	0.063

(P.S.S.= perceived social support;
**p<0.01; r= Pearson correlation)

Table 39
The relationship of perceived social support to depression (HAD): primary carer.

P.S.S.	First Line	Follow Up	Palliative
	r	r	r
Family	0.333*	0.337*	0.169
Friends	0.205	0.329*	0.207

(P.S.S.= perceived social support;
*p<0.05; r= Pearson correlation)

There is clearly a highly significant positive correlation in the first line group between social support from family and anxiety (Table 38). The remainder of the correlations between social support and anxiety fail to achieve statistical significance.

The relationship between social support and depression (Table 39) also demonstrates some significant correlations. Once again the relationship between family and mood state achieves significance as it does in the follow up group. In this latter group, however, their is a significant relationship between social support from friends and depression.

These positive correlations are contrary to the expected results. A prevalent view of perceived social support is that it acts as a "buffer" mechanism against distress [Procidano and Heller, 1983]. One would, therefore, expect significant inverse correlations to be achieved i.e. that high levels of social support would be correlated with low levels of distress. The results from the current study indicate that at specific times during the illness "process" high levels of perceived emotional social support are associated with high levels of distress. Further support for this association is found if the relationship between perceived social support and the total score of the General Health Questionnaire (GHQ) of the carer is examined. In the first line group the correlation between perceived social support from family and the GHQ score is highly significant ($r=0.435$; $p<0.01$). The relationship between perceived social support from friends and the GHQ fails to achieve significance ($r=0.144$). In the follow up group the relationship fails to achieve statistical significance (support from family, $r=0.024$; from friends, $r=0.101$). In the palliative therapy group there is no statistically significant association (family, $r=0.229$; friends, $r=0.014$).

Procidano and Heller [1983], in their original paper concerning the Perceived Social Support Scale, recommend that in addition to using correlation co-efficients to assess the scale, a median split should be performed in the scores of the scale. In this way, the impact of social support can be assessed using a

comparison of the two groups: high social support versus low social support.

A median split was, therefore, performed comparing the anxiety and depression scores of the HAD scale in patients and carers with high and low social support. There were no statistically significant differences in anxiety and depression scores in the three groups of patients when a median split was used in both subscales (family and friends) of the questionnaire.

In the three groups of carers, the results support the findings of the correlational data. The difference between anxiety scores of carers in the first line management group with high versus low social support from family achieve statistical significance. Likewise, when comparing the depression scores in the follow up group there is a statistically significant difference between patients with high versus low social support from both family and friends.

Table 40
A comparison of anxiety and depression scores of carers with high and low perceived social support scores.

	Low Social Support			High Social Support			
	N	Mean	(SD)	N	Mean	(SD)	t
PSS Family							
Anxiety (HAD):							
First Line	11	7.73	(5.39)	29	11.59	(5.23)	-2.04*
Follow up	14	8.36	(6.74)	26	10.77	(4.62)	-1.20
Palliative	14	7.71	(5.90)	26	10.42	(5.46)	0.56
Depression (HAD):							
First Line	11	4.09	(4.30)	29	6.93	(4.80)	-1.80
Follow up	14	2.93	(3.32)	26	5.50	(4.85)	-1.98*
Palliative	14	5.00	(5.42)	26	6.08	(5.64	-0.60
PSS Friends							
Anxiety (HAD):							
First Line	17	9.82	(5.51)	23	11.04	(5.54)	-0.69
Follow up	23	8.87	(5.53)	17	11.35	(5.28)	-1.44
Palliative	14	9.93	(4.91)	26	9.23	(6.15)	0.39
Depression (HAD):							
First Line	17	5.00	(4.00)	23	7.00	(5.29)	-1.36
Follow up	23	3.30	(3.36)	17	6.35	(5.31)	-2.08*
Palliative	14	5.00	(5.20)	26	6.08	(5.74)	-0.60

(* $p<0.05$)

The results, shown in Table 40, demonstrate that in all the comparisons made (with the exception of one), the trend is for those carers with high perceived social support to have higher scores on the anxiety and depression subscales of the HAD questionnaire.

One explanation for this effect is that the social support is a reaction to the distress of the carer. Such an explanation could be postulated for the carers of the first line group of patients where the anxiety score of carers with high social support is significantly higher than those with low social support

($p<0.05$). This group of patients have only recently been diagnosed (mean score since diagnosis is 1.1 months; S.D. 0.4 months) and the initial distress following diagnosis may act as a catalyst for increased levels of social support.

A similar explanation could be applied to the follow up group in that these patients have finished treatment within the last 2-3 months and carers may find the uncertainty of the future difficult to cope with and distressing. During this latter stage of management, patients (and, perhaps their carers) return to the clinic each month for tests and investigations to monitor their progress. It is a time of great uncertainty which many people find extremely stressful [Koocher and Malley, 1981]. One would also expect this effect to be true in the palliative therapy group as during this stage the patient is often very unwell with multiple symptoms.

The question regarding the effect of distress on the level of social support can be answered to some extent by analysing some of the data from the brief interview schedule relating to perceived changes in social support.

Carers were asked if there had been any change in the support that they had received from people since their husband's/ wife's/ or friend's diagnosis (Table 41). The first line management group clearly indicate that the majority of carers (70 per cent) perceive that there has been an increase in support. In the follow up group the majority (52.5 per cent) perceive that there has been a decrease in support. In the

palliative therapy group the dominant perception (60 per cent) is that there has been an increase in support. Chi square analysis reveals that these differences between the groups are highly significant (X^2= 37.82; df=4; p<0.001).

Table 41
Perceived changes in support since diagnosis: primary carer (n= 40 subjects in each group).

Support	First Line		Follow up		Palliative	
	n	(%)	n	(%)	n	(%)
No change	12	(30.0)	10	(25.0)	11	(27.5)
Increase	28	(70.0)	9	(22.5)	24	(60.0)
Decrease	0	(0.0)	21	(52.5)	5	(12.5)

In addition, carers were asked if they felt there had been any change in the support received from family and friends in the past month (Tables 42 and 43). In the three groups of carers the predominant response was that there had been no change in support from either family or friends, although a significant number in the follow up group report that there has been a decrease in support from family (X^2=17.45; df=4; p<0.01) and friends (X^2= 9.56; df= 4; p<0.05).

Table 42
Perceived change in support from family during the previous month: primary carer (n= 40 subjects in each group).

Support	First Line		Follow up		Palliative	
	n	(%)	n	(%)	n	(%)
No change	33	(82.5)	24	(60.0)	30	(75.0)
Increase	5	(12.5)	6	(15.0)	10	(25.0)
Decrease	2	(12.5)	10	(25.0)	0	(0.0)

Table 43
Perceived changes in support from friends during the previous month: primary carer (n=40 subjects in each group).

Support	First Line		Follow up		Palliative	
	n	(%)	n	(%)	n	(%)
No change	34	(85.0)	32	(80.0)	33	(82.5)
Increase	3	(7.5)	2	(5.0)	7	(17.5)
Decrease	3	(7.5.)	6	(15.0)	0	(0.0)

These questions are very general in nature in that they ask about "support". A further question was phrased more specifically in that it asked about perceived changes in availability of family and friends in whom one could confide and share worries over the past month (Tables 44 and 45).

Table 44
Perceived changes in the availability of family members in whom one could confide or share worries: primary carer (n=40 subjects in each group).

Support	First Line		Follow up		Palliative	
	n	(%)	n	(%)	n	(%)
No change	22	(55.0)	29	(72.5)	27	(67.5)
Increase	15	(37.5)	2	(5.0)	8	(20.0)
Decrease	3	(7.5.)	9	(22.5)	5	(12.5)

Table 45
Perceived changes in the availability of friends in whom one could confide or share worries: primary carer (n=40 subjects in each group).

Support	First Line		Follow up		Palliative	
	n	(%)	n	(%)	n	(%)
No change	26	(65.0)	30	(75.0)	29	(72.5)
Increase	11	(25.5)	2	(5.0)	6	(15.0)
Decrease	3	(7.5)	8	(20.0)	5	(12.5)

The results show that the majority of subjects report no change in the availability of social support from family and friends in the past month. A significant number of respondents, however, in the first line and palliative therapy groups report an increase in the availability of family members in whom they could confide, whereas a significant number in the follow up group report a decrease in the availability in family members (X^2=14.45; df= 4; $p<0.01$). A similar pattern of response is found in relation to the availability of friends, although the difference between groups fails to achieve statistical significance (X^2= 9.10; df=4; N.S.).

A comparison of Perceived Social Support Scale scores between those who perceived an increase and those who did not perceive any change in the past month did not reveal any statistically significant differences (family and friends).

The data concerning the relationship between social support and psychological state suggest that for the carer there is a statistically significant relationship between social support from family and friends and anxiety and depression. The data suggest that high levels of support are associated with high levels of distress. The perceptions of carers regarding recent changes in the availability of support suggest, tentatively, that social support changes may not necessarily be in response to distress. These associations have not been found when looking at the relationship between social support scores in the patient and anxiety and depression.

Social support and physical symptoms

The impact of symptomatology on social support was examined in patients and their carers at different stages of the illness "process".

The most striking effect of symptomatology on perceived social support was found in the first line management group of patients (Table 46). Statistically significant associations were found between the number and severity of symptoms that patients complained of and perceived social support from family and friends. The results suggest that the more symptom complaints the patient has the greater the degree of social support that they experience.

Table 46
The relationship between symptoms and their severity and perceived social support in patients undergoing first line management.

Symptoms & Side effects	Perceived Social Support	
	Family	Friends
	r	r
Number	0.351*	0.437***
Severity	0.381**	0.384**
Performance	-0.55	0.048

(Performance = Performance Status; * p<0.05; ** p<0.02; *** p<0.01; r= Pearson Correlation).

In the follow up group of patients and those receiving palliative care no statistically significant correlations were found between symptoms and side effects, performance status and perceived social support from family and friends.

The increased level of social support in the first line group could be due to the relatively recent diagnosis and the start of treatment. Friends and family may be very aware of the situation and may be responding to the initial effects of chemotherapy (nausea, vomiting and hair loss) in giving increased social support to the patient by coming to see them.

This hypothesis is supported by some of the data from the brief interview schedule of the patient. Patients were asked if there had been any change in the support that they had received since they first became ill. In response to this, 12 patients (30 per cent) felt that there had been no change, 20 patients (50 per cent) felt that there had been an increase in social support and 8 patients (20 per cent) felt that there had been a decrease in social support.

The impact of the patients' symptoms and side effects and performance status on the carers' perceived social support scores failed to achieve statistical significance. The finding was consistent in the three groups of primary carers and for perceived social support from both family and friends.

Social support and age

The relationship between social support and age revealed some interesting associations. No statistically significant correlations were found between age of the patient and perceived social support scores from family and friends in the three groups.

The primary carers, however, demonstrated the opposite. In the first line group the correlations between the carers age and social support from family and friends failed to achieve statistical significance. In the follow up group and the palliative group, however, statistically significant inverse correlations were found between social support from both family and friends and age (Table 47).

Table 47
The relationship between age and perceived social support in primary carers (n=40 subjects in each group).

P.S.S.	First Line	Follow up	Palliative
	r	r	r
Family	-0.09	-0.337*	-0.326*
Friends	-0.07	-0.404**	-0.418***

(P.S.S.= perceived social support;
* p<0.05; ** p<0.02; *** p<0.01; r= Pearson Correlation).

In the follow up group and the palliative therapy group the older the primary carer, the less social support they perceive themselves to have both from family and from friends. Interestingly, the stronger statistical relationships can be seen when correlating age with social support from friends.

Social support and personality

No statistically significant correlations were found between perceived social support and extraversion or neuroticism scores of the EPI in patients and their carers in any of the

groups. This suggests that social support is not a reaction to personality type in the respondents at any stage of the illness.

Perceived social support: sex differences

The perceived social support scores of the three groups of patients were examined in terms of sex differences. No statistically significant differences were found between males and females in social support from family and friends in any of the groups. The result remained consistent when the social support scores of the primary carers were subjected to the same analysis. No effect of sex was observed in any of the groups in terms social support from family and from friends.

Attitudes and mood

Patients were asked a series of questions regarding their attitude to their illness and its treatment. The effect of these attitudes on mood state was then examined.

The first question that patients were asked was whether they felt that it was better to try to "accept" their illness or try to "fight" it. The responses are shown for each of the three groups in Table 48.

Table 48
Attitudes of patients to their illness: "accept" versus "fight" (n=40 subjects in each group).

Attitude	First Line		Follow up		Palliative	
	n	(%)	n	(%)	n	(%)
Accept	10	(25.0)	5	(12.5)	20	(50.0)
Fight	27	(67.5)	33	(82.5)	18	(45.0)
Don't know	3	(7.5)	2	(5.0)	2	(5.0)

A chi square test reveals that there is a statistically significant difference between the distribution of attitudes of the patients in the three groups ($X^2=14.67$; df=4; $p<0.01$). Comparisons between the mean anxiety and depression scores of the HAD scale of the those who accepted their illness versus those who felt that they should fight it failed to achieve statistical significance. This result was the same in the first line management group and the palliative therapy group. The unequal distribution of attitudes in the follow up group resulting in extremely small numbers in the "accept" and "don't know" categories rendered a statistical comparison between the groups invalid.

The second question that the patients were asked was whether they felt hopeful or pessimistic about the future. The responses are shown in Table 49.

Table 49
Attitudes of patients to their future: pessimistic versus hopeful (n=40 subjects in each group).

Attitude	First Line		Follow up		Palliative	
	n	(%)	n	(%)	n	(%)
Pessimistic	4	(10.0)	3	(7.5)	17	(42.5)
Hopeful	34	(85.0)	30	(75.0)	23	(57.5)
Don't know	2	(5.0)	7	(17.5)	0	(0.0)

A chi square test between the groups reveals that there is a statistically significant difference between the responses of the groups (X^2= 26.05; df=4; p<0.001). This can be seen in the palliative therapy group where the distribution of responses is more even than the two other groups.

The distribution of attitudes in the palliative therapy group is such that a comparison can be made between the mood state of those patients who are pessimistic about the future and those who are hopeful. In fact, comparisons between the anxiety and depression scores of the HAD scale in these two groups failed to achieve statistical significance. The distributions of attitude in the first line management group and follow up group made comparisons of mood state invalid.

The third question that patients were asked was whether they preferred to leave decisions about their treatment to the doctors or whether they preferred to have a say in these decisions. The responses are shown in Table 50.

Table 50
Attitudes of patients to participation in their treatment decisions: "passive" versus "active" (n=40 patients in each group).

Attitude	First Line		Follow up		Palliative	
	n	(%)	n	(%)	n	(%)
Passive	11	(27.5)	4	(10.0)	11	(27.5)
Active	27	(67.5)	31	(77.5)	26	(65.0)
Don't know	2	(5.0)	5	(12.5)	3	(7.5)

A chi square test between the responses of the three groups failed to achieve statistical significance suggesting that there is no significant difference between the distribution of attitudes of the three groups of patients (X^2=5.67; df=4; p=0.30).

A comparison of anxiety and depression scores on the HAD scale between those who were passive and those were active in the first line group and the palliative therapy group failed to achieve statistical significance. The distribution of responses in the follow up group was such that comparisons of the impact of attitude on mood state were invalid.

The results of the analysis of the impact of patients attitudes to their illness and its treatment on anxiety and depression suggest that there is no significant effect at any of the three stages.

The primary carers were asked a similar series of questions concerning attitudes to illness and treatment. The first question was concerned with whether they felt it better for their husband/ wife/ friend to try to accept the illness or to try to fight it (Table 51).

This data represents a very crude division of attitudes in patients and primary carers. This data, therefore, must be treated with caution as independent ratings were not obtained to confirm the allocation of patients to these categories and the resulting division is, as a result, open to criticism.

Table 51
Attitudes of carers to illness: "accept" versus "fight" (n= 40 subjects in each group).

Attitude	First Line		Follow up		Palliative	
	n	(%)	n	(%)	n	(%)
Accept	3	(7.5)	4	(10.0)	21	(52.5)
Fight	35	(87.5)	28	(70.0)	18	(45.0)
Don't know	2	(5.0)	8	(20.0)	1	(2.5)

A chi square test between the distribution of responses in the three groups reveals that there is a statistically significant difference between the groups (X^2=35.15; df=4; p<0.001). The distribution of attitudes is more even in the palliative group. A comparison of anxiety and depression scores from the HAD scale between the "accept" and "fight" responders in this latter group failed to achieve statistical significance. No comparisons were made in the first two groups due to the extremely skewed distributions of attitudes creating extremely small numbers in some of the categories.

The second question that carers were asked was whether they felt hopeful or pessimistic about the future (Table 52).

Table 52
Attitudes of carers to the future: hopeful versus pessimistic (n=40 subjects in each group).

Attitude	First Line		Follow up		Palliative	
	n	(%)	n	(%)	n	(%)
Pessimistic	19	(47.5)	3	(7.5)	29	(72.5)
Hopeful	19	(47.5)	27	(67.5)	9	(22.5)
Don't know	2	(5.0)	10	(25.0)	2	(5.0)

A chi square test between the distribution of responses of the three groups achieved statistical significance (X^2=38.25; df=4;

p< 0.001), thus indicating that there is a difference in attitudes in three groups. A comparison of the HAD scale, anxiety and depression scores in the first line group and the palliative therapy group between attitudes (pessimistic versus hopeful) showed no statistically significant difference. The distribution of responses in the follow up group was so skewed as to render a comparison of mood state invalid.

The third question that the carers were asked was whether they preferred to leave decisions about their husband's/ wife's/ friend's treatment to the doctor or whether they preferred to have a say in these decisions (Table 53).

Table 53
Attitudes of carers to participation in treatment decisions: passive versus active (n=40 subjects in each group).

Attitude	First Line		Follow up		Palliative	
	n	(%)	n	(%)	n	(%)
Passive	25	(62.5)	3	(7.5)	22	(55.0)
Active	10	(25.0)	29	(72.5)	17	(42.5)
Don't know	5	(12.5)	8	(20.0)	1	(2.5)

A chi square test revealed there to be statistically significant differences between the groups in the distribution of attitudes to participation in treatment decisions (X^2=32.26; df=4; p<0.001). The distribution of attitudes in the first line group and the palliative group enabled the effect of attitude on HAD scale, anxiety and depression scores to be examined. No statistically significant difference was found between the mood state scores of carers who were "passive" in treatment

decisions versus those who were "active". The distribution of attitude responses in the follow up group was too skewed to enable a valid comparison of mood state scores to be performed.

The distribution of attitude responses in carers, therefore, is significantly different between the three groups. The data suggest, however, that attitudes do not significantly affect anxiety and depression scores of carers at any stage of the illness "process".

The impact of the illness and its treatment on psychosocial adjustment.

Patients

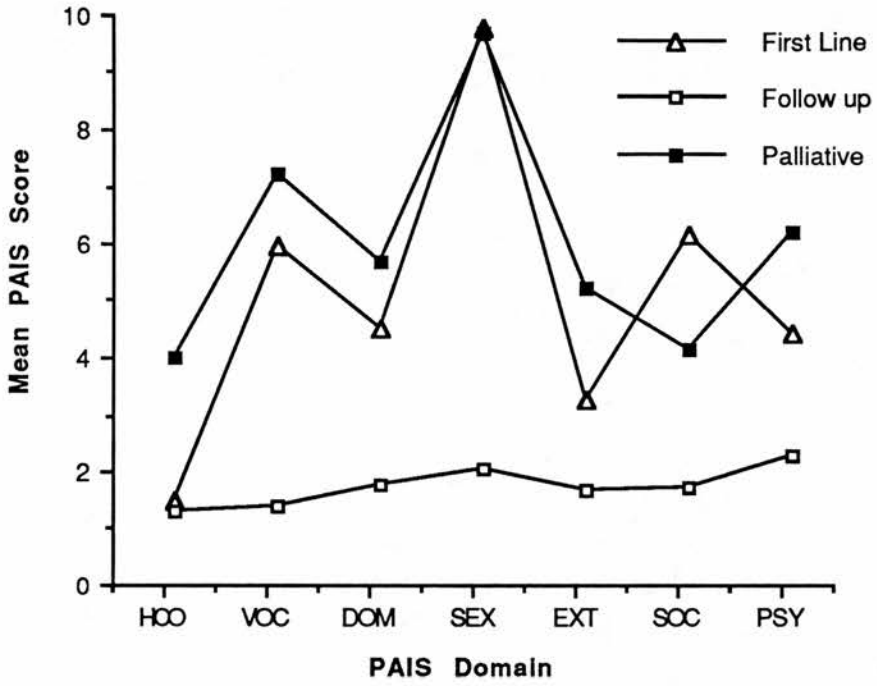
Patients in the three "management" groups completed the Psychosocial Adjustment to Illness Scale (PAIS) [Derogatis, 1976; 1983]. The data from the three groups was then subjected to an analysis of variance (Table 54). In analysing data from the PAIS, raw scores were used as recommended by the authors in the Test Manual [Derogatis, 1983 (p19)]. Higher scores on this test suggest greater adjustment problems.

Table 54
Analysis of variance of PAIS scores by domain: patient (means, standard deviations and F ratios) (n=40 subjects in each group).

PAIS Domain	First line Mean (S.D.)	Follow up Mean (S.D.)	Palliative Mean (S.D.)	F ratio	Significance
Health care orientation	1.30 (1.40)	1.12 (1.22)	3.82 (3.51)	17.33	p< 0.0001
Vocational Environment	5.75 (5.40)	1.22 (1.39)	7.02 (4.98)	19.95	p< 0.0001
Domestic Environment	4.32 (3.44)	1.57 (1.66)	5.50 (3.94)	16.20	p< 0.0001
Sexual relationship	9.60 (3.64)	1.87 (2.55)	9.47 (4.83)	54.53	p< 0.0001
Extended family	3.07 (2.37)	1.50 (2.08)	5.00 (3.41)	17.06	p< 0.0001
Social Environment	5.97 (3.57)	1.52 (1.55)	3.97 (3.47)	21.93	p< 0.0001
Psychologic. Distress	4.22 (3.06)	2.10 (2.26)	6.00 (3.57)	16.79	p< 0.0001
Total	34.25 (9.69)	10.93 (10.64)	40.80(20.58)	46.92	p< 0.0001

The analysis of variance by PAIS domain reveals that there is a statistically significant difference between the three groups in each domain and including the total. These relationships are illustrated in Graph 6, where it can clearly be seen that the follow up group tends to experience less impact on adjustment than the other groups.

Graph 6. PAIS Scores by Domain: Patient Groups.



(**HCO**= Health care orientation; **VOC**= Vocational environment; **DOM**= Domestic environment; **SEX**= Sexual relationships; **EXT**= Extended family relationships **SOC**= Social environment; **PSY**= Psychological distress)

Scheffe's multiple range test was utilised to investigate further these significant differences between the three groups. Psychosocial adjustment in "health care orientation" was found to be significantly poorer in the palliative therapy group than in the first line group and the follow up group (First line versus palliative: F= 24.19; df = 2, 117; p <0.001. Follow up versus palliative: F= 27.66; df = 2, 117; p <0.001.)

This suggests a deterioration in "health care posture" when the patient relapses but a preservation of health seeking behaviours during the initial chemotherapy and follow up surveillance.

The patients' "vocational environment" score which reflects the impact of the illness and its treatment on employment demonstrates a different pattern. Not surprisingly, there is a statistically significant difference between the first line management group and the follow up group ($F= 22.06$; $df = 2, 117$; $p <0.001$) and between the follow up group and the palliative group in this domain ($F= 36.17$; $df= 2, 117$; $p<0.001$). This suggests that the impact on the respondent's work is greater during initial chemotherapy but this impact is not significantly different between these two stages.

The same picture emerged in the "domestic environment" domain which assesses illness induced difficulties that arise in the home or family environment. The most significant impact was found during first line chemotherapy and palliative therapy (first line versus follow up $F= 15.12$; $df= 2, 117$; $p<0.001$; follow up versus palliative $F= 30.88$; $df=2,117$; $p<0.001$) but the difference between these two did not achieve statistical significance.

The same pattern of results emerged again in the "sexual relationship" domain which assesses the impact of the illness on sexual functioning. The most significant impact was found during first line chemotherapy and palliative therapy (first line versus follow up $F=82.99$; $df=2, 117$; $p<0.001$; follow up versus palliative therapy $F=80.20$; $df= 2, 117$; $p<0.001$) but again the difference between these two was not statistically significant.

The pattern of results for the domain "extended family" was slightly different. This domain assesses the disruption in relationships with extended family relationships that are associated with the illness and its treatment. There was a statistically significant difference between all three comparisons. The first line management group showed significantly poorer adjustment than the follow up group ($F=6.80$; $df=2,117$; $p<0.001$). The follow up group showed significantly better adjustment than the palliative group ($F=34.02$; $df=2,117$; $p<0.001$) and the palliative therapy showed significantly poorer adjustment than the first line group ($F=10.35$; $df=2,117$; $p<0.001$). This data suggest, therefore, that the palliative therapy stage of the illness has the greatest derangement of extended family relationships.

In the "social environment" domain, however, the greatest effect was seen during the first line chemotherapy. Adjustment between the first line group and follow up group was significantly poorer in the first line group ($F=43.80$; $df=2,117$; $p<0.001$). The palliative group showed greater disruption than the follow up group ($F=13.28$; $df= 2,117$; $p<0.001$) and the first line group showed greater disruption than the palliative group ($F=8.85$; $df=2,117$; $p<0.001$).

The "psychological distress" domain which is a global measure of distress (with components of anxiety, depression, hostility, reduced self esteem, body image problems, and guilt) showed the greatest impact to be in the palliative therapy group. The

scores in this domain were significantly worse than in the first line group ($F=6.98$; $df=2,117$; $p<0.01$) and the follow up group ($F=33.50$; $df=2,117$; $p<0.001$). The first line group also had more distress than the follow up group ($F=9.89$; $df= 2,117$; $p<0.001$).

The total score which gives a global measure of psychosocial adjustment to illness was found to be significantly worse in the palliative therapy group when compared to the first line group ($F=4.18$; $df= 2,117$; $p <0.025$) and the follow up group ($F=87.04$; $df =2,117$; $p<0.001$). The first line group also showed poorer adjustment than the follow up group ($F=53.05$; $df=2,117$; $p<0.001$).

This suggests that the patients undergoing palliative therapy experience the poorest adjustment to their illness and its treatment.

Primary carers

The primary carers in the three groups also completed the Psychosocial Adjustment to Illness Scale (PAIS) and the data was subjected to an analysis of variance (Table 55).

Table 55
Analysis of variance of PAIS scores by domain : carer. Means, standard deviations and F-ratios (n=40 subjects in each group).

PAIS Domain	First line Mean (S.D.)	Follow up Mean (S.D.)	Palliative Mean (S.D.)	F ratio	Significance
Health care orientation	3.22 (2.29)	2.05 (2.71)	5.0 (3.01)	12.19	p <0.0001
Vocational Environment	5.52 (3.62)	1.70 (1.84)	7.72 (3.28)	40.87	p<0.0001
Domestic Environment	3.37 (3.13)	2.50 (3.00)	4.62 (2.77)	5.16	p=0.007
Sexual relationship	6.67 (3.93)	3.62 (3.87)	7.35 (3.57	10.93	p<0.0001
Extended family	4.27 (3.65)	2.37 (2.69	4.90 (2.93)	7.09	p<0.001
Social Environment	7.37 (4.01)	2.37 (2.27)	7.72 (4.25)	27.32	p<0.0001
Psychologic. Distress	5.32 (3.08)	4.12 (3.55)	7.97 (4.30)	11.47	p<0.0001
Total	35.78 (7.37)	18.75 (16.64)	45.30(12.00)	45.69	p<0.0001

The analysis of variance reveals that there are statistically significant differences between the groups in each domain of the PAIS scale. These differences are illustrated in Graph 7 where the trend suggests that the follow up group experience less impact on adjustment than the other two groups.

These significant differences were then examined more closely using Scheffe's multiple range test.

In the "health care orientation" domain the palliative therapy group had significantly higher scores and therefore poorer adjustment than either of the other two groups (palliative therapy versus first line group F=8.70; df=2,117; p<0.001: and versus the follow up group F=24.04; df=2,117; p<0.001). There

was however no statistically significant difference in scores between the first line group and the follow up group.

In the "vocational environment" domain, there was a statistically significant difference between all three groups. The first line group had significantly higher scores ($F=32.15$; $df=2,117$; $P<0.001$) but significantly lower than the palliative therapy group ($F=10.63$; $df=2,117$; $p<0.001$). The difference between the follow up group and palliative group was also significant ($F=79.78$; $df=2,117$; $p<0.001$). This suggests that the palliative therapy group have poorer adjustment than either of the others.

The "domestic environment" domain scores were highest in the palliative therapy group. There was no statistically significant difference between the first line group and the follow up group. However, differences between the first line group and the palliative group ($F=3.53$; $df=2,117$; $p<0.05$) and the follow up group and the palliative group ($F=10.20$; $df=2,117$; $p<0.001$) did achieve statistical significance.

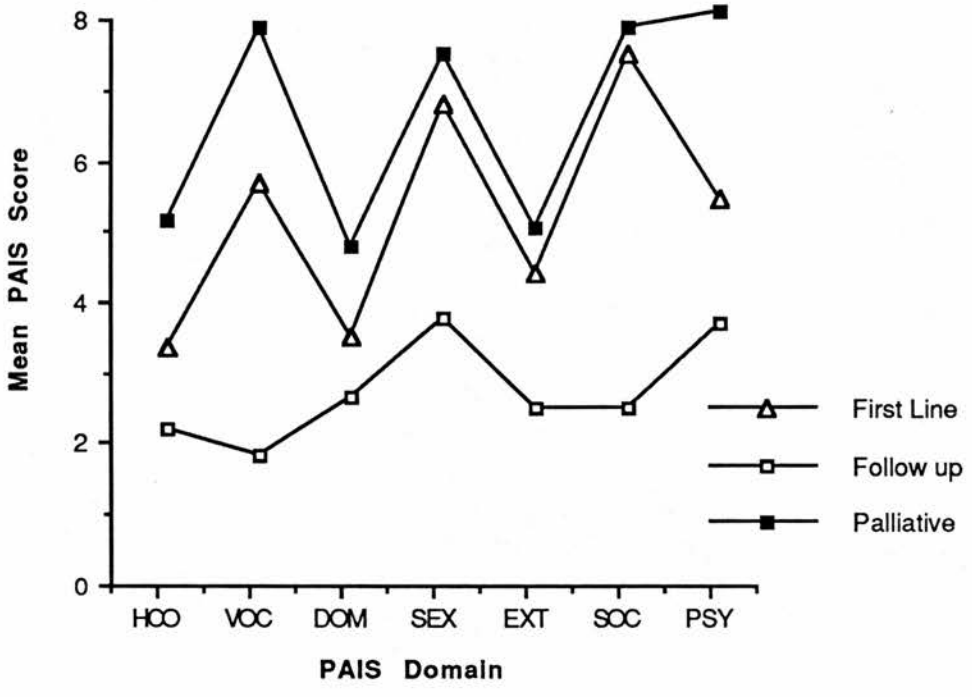
Sexual relationship scores were highest in the first line group and the palliative therapy, there was no statistically significant difference between them. However, both the first line group and the follow up group ($F=12.92$; $df=2,117$; $p<0.0001$) and the follow up group and the palliative group ($F=19.27$; $df=2,117$; $p<0.001$) had statistically significant differences between them.

A similar picture was found in the "extended family" domain where both the first line group and the palliative group had significantly higher scores than the follow up group ($F=3.90$; $df= 2,117$; $p<0.05$; and $F= 13.09$; $df= 2, 117$; $p<0.001$). This pattern was also repeated in the "social environment" domain where both the first line group and the palliative group had higher scores than the follow up group ($F=38.00$; $df=2,117$; $p<0.001$ and $F=43.69$; $df=2,117$; $P<0.001$).

The domain of "psychological distress" revealed that the scores between the first line group and the follow up group were not significantly different. The palliative therapy group, however, had significantly higher scores than either of the other two groups (palliative therapy versus the first line group $F=10.40$; $df=2,117$; $p<0.001$ and versus the follow up group $F=21.95$; $df=2,117$; $p<0.001$). This suggests that like the patient groups the greatest degree of psychological distress is found in the palliative therapy group.

The "total" score of the PAIS was found to be significantly worse in the palliative therapy group when compared to the first line group ($F=11.47$; $df=2,117$; $p<0.001$) and the follow up group ($F=89.22$; $df=2,117$; $p<0.001$). There was also a significant difference between the first line group and the follow up group ($F=36.71$; $df=2,117$; $p<0.001$). This pattern mirrors that seen in patients, the highest level of disruption found in the palliative therapy group followed by the first line group and the follow up group.

Graph 7. PAIS Scores by Domain: Carers



(HCO= Health care orientation; VOC= Vocational environment; DOM= Domestic environment; SEX= Sexual relationships; EXT= Extended family relationships SOC= Social environment; PSY= Psychological distress)

Psychological Adjustment to Illness Scale (PAIS): differences between patients and their primary carers.

Comparisons were made between the PAIS domain mean scores of patients and their primary carers. The statistically significant differences for the first line group are shown in Table 56.

Table 56
Statistically significant differences in PAIS domains: patient and primary carer (first line management). (n=40 pairs in each group.)

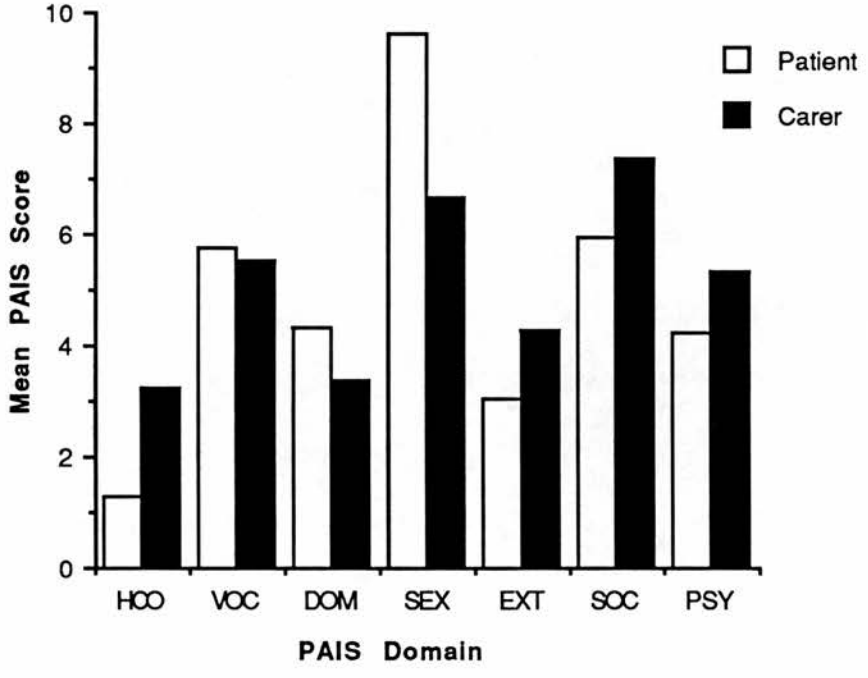
Domain	Patient	Primary Carer	t	Significance
	Mean (S.D.)	Mean (S.D.)		
Health Care Orientation	1.30 (1.40)	3.22 (2.29)	-4.53	p<0.0001
Sexual relationship	9.60 (3.64)	6.67 (3.93)	3.45	p=0.0009

Comparisons using T-tests between the remaining domains for the first line management group failed to achieve statistical significance. The statistically significant differences (Table 56) suggest that the primary carer experiences greater disruption of "health care posture" than the patient. It suggests that the carer has more negative views about the doctors, the treatment, and the future. In addition, it suggests that the primary carer feels that they are more lacking in information concerning the illness and its treatment than the patient.

The patient, however, experiences greater disruption of sexual relationships and sexual interest than the primary carer during this time. This result may not be surprising given that the patient is receiving chemotherapy at this time. Correlations between the patients' PAIS domain score and the number of symptoms ($r = -0.28$) and their severity ($r = -0.26$) fail to achieve statistical significance. This is also the case when examining the relationship of number of symptoms ($r = 0.007$) and their severity ($r = 0.51$) and health care orientation scores of the primary carer.

The relationship between the PAIS domains of the patient and their carers in the first line management group are illustrated in Graph 8. This graph not only includes those domains where the difference achieves statistical significance but also includes those where it does not.

Graph 8. PAIS Domain Scores: Patient and Carer, First Line Management Group.



(HCO= Health care orientation; VOC= Vocational environment; DOM= Domestic environment; SEX= Sexual relationships; EXT= Extended family relationships SOC= Social environment; PSY= Psychological distress)

The patients and their primary carers in the follow up surveillance group demonstrated a different pattern of significant differences in PAIS domain mean scores. These are shown in Table 57.

Table 57
Statistically significant differences in PAIS domains: patient and primary carer (follow up surveillance), (n = 40 pairs in each group).

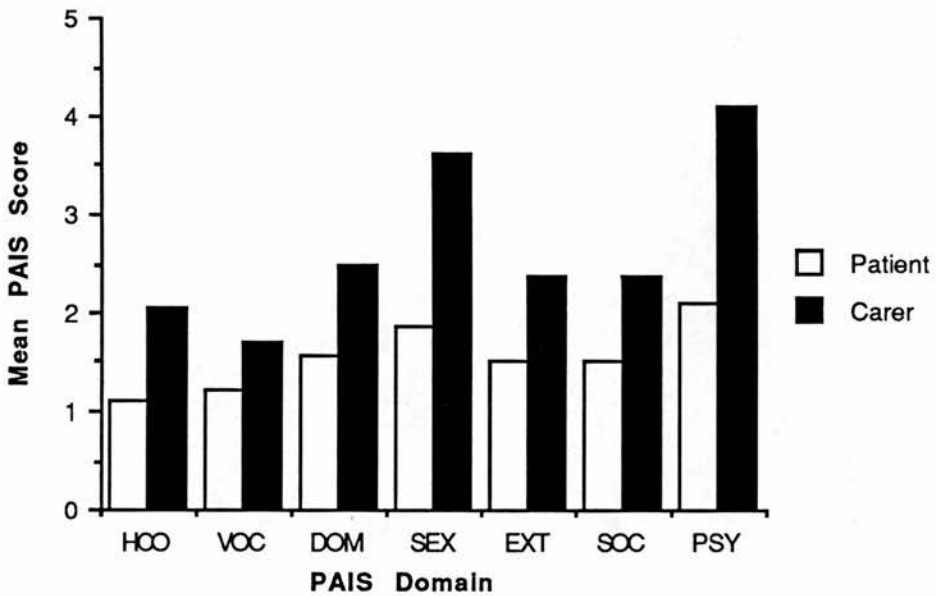
PAIS Domain	Patient Mean (S.D.)	Primary Carer Mean (S.D.)	t	Significance
Health Care Orientation	1.12 (1.22)	2.05 (2.71)	-1.96	p< 0.05
Sexual relationship	1.87 (2.55)	3.62 (3.87)	-2.39	p< 0.02
Social environment	1.52 (1.55)	2.37 (2.27	-1.95	p< 0.05
Psychological distress	2.10 (2.26)	4.12 (3.55)	-3.04	p = 0.003
Total score	10.93(10.64)	18.75(16.64)	-2.51	p< 0.01

The differences between the means of the remaining PAIS domains failed to achieve statistical significance. The results shown in Table 57 suggest that adjustment in these domains in the carer is significantly poorer than in the patient. In addition to higher scores in health care orientation and sexual relationships, carers experience a greater disruption to their social environment and experience higher levels of psychological distress than the patient. They also have a higher "total" score suggesting greater adjustment problems generally.

The relationship between the PAIS domain scores of the patient and their carers in the follow up surveillance group is illustrated in Graph 9. This includes all the PAIS domains, those where the difference between patient and carer achieve

statistical significance and those where it does not. Correlations between the number of symptoms and severity of symptoms and PAIS domains of both the patient and the carer fail to achieve statistical significance.

Graph 9. PAIS Domain Scores: Patient and Carers, Follow up Surveillance Group.



(HCO= Health care orientation; VOC= Vocational environment; DOM= Domestic environment; SEX= Sexual relationships; EXT= Extended family relationships SOC= Social environment; PSY= Psychological distress)

A comparison of the PAIS domain scores in the palliative therapy group presents yet another picture. The statistically significant differences are shown in Table 58.

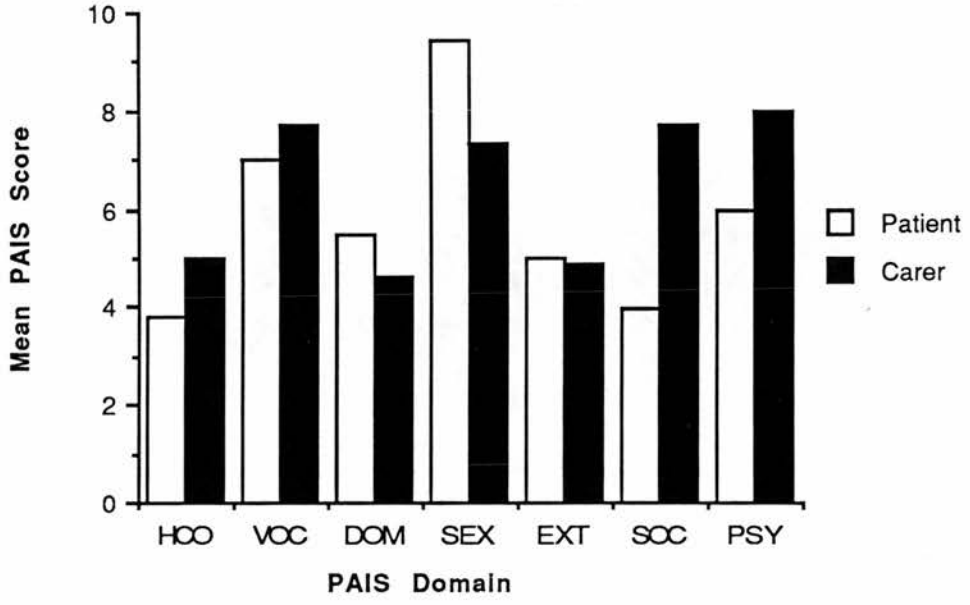
Table 58
Statistically significant differences in PAIS domains: patient and primary carer (palliative therapy). (n= 40 pairs in each group).

PAIS Domain	Patient Mean (S.D.)	Primary Carer Mean (S.D.)	t	Significance
Sexual relationship	9.47 (4.83)	7.35 (3.57)	2.24	p = 0.02
Social environment	3.97 (3.47)	7.72 (4.25)	-4.32	p<0.0001
Psychological distress	6.00 (3.57)	7.97 (4.30)	-2.23	p = 0.02

Differences between the patient and the primary carer in the remaining PAIS domains failed to achieve statistical significance. The results from Table 58 suggest that the patient experiences greater disruption in sexual relationships than the primary carer during palliative therapy. The carer, however, experiences greater disruption in social environment and psychological distress during this time.

The relationship between the PAIS domain scores of the patient and their carer in the palliative therapy group are shown in Graph 10. This graph includes all the PAIS domains: those where the difference between patients and carer achieves statistical significance and those where it does not.

Graph 10. PAIS Domain Scores: Patient and Carer, Palliative Therapy Group.



(**HCO**= Health care orientation; **VOC**= Vocational environment; **DOM**= Domestic environment; **SEX**= Sexual relationship; **EXT**= Extended family relationship; **SOC**= Social environment; **PSY**= Psychological distress).

Correlations between the PAIS domain scores of the patient and the PAIS domain scores of the carer failed to achieve statistical significance in any of the three groups. This suggests that there is little association between the patient and carer in terms of psychosocial adjustment.

Correlations between symptoms and their severity achieved statistical significance with respect to the "vocational environment" of the patient, not surprisingly. Correlations with both the number of symptoms ($r=0.36$; $p<0.05$) and their severity ($r= 0.38$; $p<0.05$) and the vocational domain were significant. Similarly, a correlation between the severity of symptoms and the extended family domain ($r= 0.37$; $p<0.05$) achieved statistical significance, again not surprisingly. No

correlations between symptoms and their severity and PAIS domain scores in the carer achieved statistical significance.

None of the correlations between measures of perceived social support from family and friends and any of the PAIS domains achieved statistical significance. This effect was consistent for both patients and carers at all stages of the illness "process". The same result was found when correlations were performed between age and PAIS domains, none achieved statistical significance.

Psychosocial Adjustment to Illness Scale (PAIS): sex differences.

The effect of sex was examined in each of the PAIS domains in both domains in both patients and their primary carers. There were no statistically significant differences between males and females in any of the PAIS domains. This result remained consistent in both patients and the primary carer in the three stages of the illness/treatment process. (This included the PAIS domains and the PAIS "Total" score.)

The impact of the illness and its treatment on different aspects of patients and carers lives: questionnaire data.

A series of questions was asked concerning the impact of the illness and its treatment on different aspects of patients and their primary carers' lives. These questions formed Part 1 of the Brief Interview Schedule.

Questions were posed concerning the main worries of patients and carers regarding their illness and its treatment. The results are shown in Table 59 and 60 for the three management groups.

Table 59
The main worries of patients and carers regarding their illness (n= 40 subjects in each group).

Main Worry	First Line		Follow up		Palliative	
	Patient	Carer	Patient	Carer	Patient	Carer
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
Not getting better	16 (40)	14(35)	0 (0)	0 (0)	8(20)	9(22.5)
Effect on family	13(32.5)	13(32.5)	8(20)	10(25)	14(35)	15(37.5)
Pain/suffering	6(15)	3(7.5)	0(0)	0(0)	15(37.5)	10(25)
Perm. disabled	0(0)	3(7.5)	0(0)	0(0)	0(0)	0(0)
Death	3(7.5)	4(10)	2(5)	6(15)	2(5)	6(15)
Return of disease	0(0)	0(0)	18(45)	18(45)	0(0)	0(0)
None	2(5)	3(7.5)	12(30)	6(15)	1(2.5)	0(0)

The results shown in Table 59 show a remarkable similarity between the worries of the patient and the carer regarding the illness. There is a statistically significant change in the nature of concerns across the group of both patients (X^2=69.74; df=12; p<0.001) and carers (X^2= 63.03; df=12; p<0.001). The first line and palliative therapy groups are predominantly concerned with the patient "not getting better", "the effect of the illness on the family" and "pain and suffering". The follow up group who are not receiving treatment and have fewer symptoms and side effects and a better performance status are concerned predominantly with return of the disease, effects on the family or have no concerns at all.

Table 60
Main worries of patients and their carers about treatment (n= 40 subjects in each group).

Main Worry	First Line		Follow up		Palliative	
	Patient	Carer	Patient	Carer	Patient	Carer
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
Side effects	24(60)	16(40)	2(5)	5(12.5)	6(15)	3(7.5)
Non control of symptoms.	5(12.5)	5(12.5)	6(15)	6(15)	12(30)	23(57.5)
Treat. ineffective	3(7.5)	7(17.5)	2(5)	9(22.5)	12(30)	7(17.5)
Pain /suffering	4(10)	6(15)	2(5)	6(15)	6(15)	5(12.5)
Effect of lifestyle	0(0)	4(10)	0(0)	5(12.5)	0(0)	0(0)
Req. more treat.	0(0)	0(0)	10(25)	3(7.5)	3(7.5)	0(0)
None	4(10)	2(5)	18(45)	6(15)	1(2.5)	2(5)

(Treat. ineffective= treatment ineffective at shrinking tumour
Req. more treat.= requiring more treatment)

Table 60 shows the main worries of patients and carers regarding the treatment. There is a statistically significant difference across the groups of patients (X^2= 75.83; df= 12;$p<0.001$) and carers (X^2= 44.64; df= 12; $p<0.001$). In the first line group the patients are more concerned with side effects of their treatment than carers. In the follow up group the majority of patients say they do not have any worries regarding treatment whereas the carers tend to be distributed across a range of concerns. In the palliative therapy group, carers are predominantly concerned with the treatment not controlling the patients symptoms (57.5 per cent) whereas 60 per cent of patients are divided between the treatment not controlling their symptoms and the treatment being ineffective in shrinking their tumour.

Patients and their carers were also asked about their hopes and expectations of treatment and the aims of treatment. The responses to these questions are shown in Tables 61 and 62.

Table 61
The hopes and expectations of treatment of patients and their primary carers (n= 40 subjects in each group).

Hopes/ Expectations	First Line		Follow up		Palliative	
	Patient	Carer	Patient	Carer	Patient	Carer
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
Relieve symptoms	3(7.5)	1(2.5)	6(15)	3(7.5)	9(22.5)	25(62.5)
Long term control	18(45)	26(65)	25(62.5)	19(47.5)	13(32.5)	13(32.5)
Relieve symptoms and long term control	16(40)	7(17.5)	3(7.5)	3(7.5)	13(32.5)	1(2.5)
Cure disease	3(7.5)	6(15)	1(2.5)	12(30)	5(12.5)	1(2.5)
Don't know	0(0)	0(0)	5(12.5)	3(7.5)	0(0)	0(0)

Chi square analysis shows a significant change between groups of patients (X^2= 28.25; df= 8; $p<0.001$) and carers (X^2= 61.74; df=8; $p<0.001$). These results indicate that in the first line group, patients are divided in their requirements of treatment between long term control of the disease and a combination of symptom control and long term control. The majority of carers, on the other hand, require long term control of the illness. In the follow up group, however, the majority of patients require long term control as do the carers. In this latter group it is noticeable that 12 (30 per cent) of the carers said that they required "cure" of the disease as a treatment requirement. In the palliative group, the majority of carers require treatment to relieve symptoms (62.5 per cent) although about a third still require long term control. The patients, on the other hand, are distributed between the relief of symptoms (22.5 per cent), long term control (32.5 per cent) and a combination of

the two (32.5 per cent). Interestingly in this group five patients (12.5 per cent) still require cure of the disease.

Table 62
The patients and their primary carers' perceptions of the aims of treatment.(n= 40 subjects in each group)

Perception of Treatment	First Line		Follow up		Palliative	
	Patient	Carer	Patient	Carer	Patient	Carer
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
Control disease	27(67.5)	32(80)	3(7.5)	4(10)	12(30)	5(12.5)
Cure disease	9(22.5)	6(15)	0(0)	0(0)	14(35)	5(12.5)
Monitor progress	0(0)	0(0)	35(87.5)	32(80)	0(0)	0(0)
Relieve symptoms	0(0)	0(0)	0(0)	0(0)	10(25)	21(52.5)
Don't know	4(10)	2(5)	2(5)	4(10)	4(10)	9(22.5)

Chi square analysis across the three groups of patients (X^2=125.38; df=10; $p<0.001$) and carers (X^2=155.65; df=10; $p<0.001$) reveals statistically significant differences. The majority of patients and their carers in the first line management group understood that the aim of treatment was to control the disease. A significant number of both patients and carers in this group, however, report that the aim of treatment is to cure the disease. In the follow up group the majority of both patients and their carers reported that the aim of treatment was to monitor progress and that this involved a policy of "watch and wait". In the palliative therapy group the majority of carers understood that the aim of treatment was to relieve symptoms and a quarter of the patients understood this to be the aim of treatment. A significant number of carers, however, thought that the aim of

treatment at this stage was to control the disease (12.5 per cent), 22.5 per cent did not know the aim of treatment and 12.5 per cent believed that the aim was to cure the illness. In the patient group, 30 per cent thought that the aim of treatment at this stage (palliative therapy) was to control the disease and 35 per cent that the aim was "cure". The scores for anxiety and depression of those patients and carers who thought the aim of palliative therapy was to cure the disease were compared with those who believed the aim of treatment was to control it or relieve symptoms. There was no statistically significant difference between them (Tables 63 and 64).

Table 63
Analysis of variance of patients HAD anxiety and depression scores and aim of treatment: means, standard deviations and F-Ratio.

	Control disease	Symptom relief	Cure	F	Significance
	Mean(SD)	Mean(SD)	Mean(SD)		
	(n=12)	(n=10)	(n=14)		
Anxiety	7.33(3.34)	5.30(3.30)	6.79(5.26)	0.68	N.S.
Depression	3.17(3.82)	4.60(3.66)	4.14(3.41)	0.56	N.S.

Table 64
Analysis of variance (non-parametric) of carers' HAD anxiety and depression scores and aim of treatment: medians, H value (adjusted) and significance.

	Control disease	Symptom relief	Cure	H (adj)	Significance
	Median	Median	Median		
	(n=5)	(n=21	(n=5)		
Anxiety	14.00	12.00	14.00	0.723	N.S.
Depression	4.00	4.00	3.00	0.435	N.S.

(adj= adjusted H value)

Those patients and relatives, therefore, who believed that the aim of treatment during palliative therapy was "cure" did not display significantly different scores for anxiety and depression. Thus, if this belief is regarded as the coping style "denial" if does not appear to be associated with elevated or reduced levels of distress. There is however, no firm evidence that this is denial.

Patients and carers were invited to comment on the amount of time that they gave to thinking about the illness (Table 65).

Table 65
The amount of time spent thinking about the illness (n=40 subjects in each group).

Time	First Line		Follow up		Palliative	
	Patient	Carer	Patient	Carer	Patient	Carer
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
On mind all time	4(10)	18(45)	10(25)	26(65)	13(32.5)	23(57.5)
Sometimes on mind	20(50)	11(27.5)	21(52.5)	6(15)	11(27.5)	12(30)
Try not to think about it	15(37.5)	10(25)	4(10)	3(7.5)	5(12.5)	3(7.5)
Don't think about it	1(2.5)	1(2.5)	5(12.5)	5(12.5)	11(27.5)	2(5)

Chi square analysis between the three groups of patients reveals that there is statistically significant difference between them (X^2= 26.36; df =6; $p<0.001$). There is, likewise, a statistically significant difference between the three groups of carers (X^2=12.98; df =6; $p<0.05$). The carers in the three groups are also more likely than the patients to be thinking about the illness all the time (X^2=17.55; df=2; $p<0.001$).

Talking about the illness was investigated in a similar fashion (Table 66).

Table 66
Attitudes of patients and carers to talking about their illness (n=40 subjects in each group).

Attitude	First Line		Follow up		Palliative	
	Patient	Carer	Patient	Carer	Patient	Carer
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
Talk about illness openly	12(30)	15(37.5)	18(45)	11(27.5)	10(25)	15(37.5)
Selected people at selected times	20(50)	14(35)	10(25)	17(42.5)	12(30)	20(50)
Only if asked	3(7.5)	7(17.5)	5(12.5)	9(22.5)	9(22.5)	2(5)
Avoid the subject	5(12.5)	4(10)	7(17.5)	3(7.5)	9(22.5)	3(7.5)

Chi square analysis across the three groups of patients and the three groups of carers reveals that there is no statistically significant difference in each case. Thus, this suggests that the stage of the illness does not effect the willingness to talk about it.

When asked to identify the person who most helped them cope with difficulties relating to the illness and its treatment, some interesting differences were highlighted (Table 67).

Table 67

The person who has helped patients and carers cope with difficulties arising from the illness and its treatment (n= 40 subjects in each group). (See question 9, p477 and question 9, p483.)

Person	First Line		Follow up		Palliative	
	Patient	Carer	Patient	Carer	Patient	Carer
Doctor	3	4	1	3	0	0
Nurse	3	3	2	14	0	0
Other Patient	0	0	1	16	9	0
Spouse	16	13	27	5	23	10
Relative	8	2	3	2	6	19
Friend	7	15	6	1	2	11
Minister	3	3	0	0	0	0

Both patients and their primary carers identify each other (spouse) as being the person who has helped them cope. This is consistent across the groups. In the follow up groups of carers, however, they identify other patients and nurses as being the person who has helped them most. Further questioning of this group revealed that as they perceived the "patient" to be physically well, they felt that they could not burden them with their fears and worries and therefore tended to turn elsewhere for support. The carers of patients receiving palliative therapy described relatives and friends as being the people who helped them most. This is not surprising given that the patients are physically quite unwell at this time although 25 per cent of carers still describe the "patient" as being the person who has helped them most.

The majority of patients and carers felt that they knew people who could give them support if they needed it. This was consistent, irrespective of the stage of the illness. Very few

people responded that they did not know anyone who could give them help and support (Table 68).(See question VI, p478 and question VI, p484.)

Table 68
People identified by patients and carers as able to give help and support (n= 40 subjects in each group).

Person identified as support	First Line		Follow up		Palliative	
	Patient	Carer	Patient	Carer	Patient	Carer
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
No support	1(2.5)	2(5)	4(10)	5(12.5)	7(17.5)	3(7.5)
Friends	10(25)	12(30)	5(12.5)	6(15)	10(25)	10(25)
Relatives	15(37.5)	12(30)	17(42.5)	15(37.5)	10(25)	12(30)
Friends&rels.	4(10)	14(35)	14(35)	14(35)	13(32.5)	15(37.5)

(rels= relatives)

Chi square analysis between the three groups of patients reveals a statistically significant difference (X^2=13.00; df=6; $p<0.05$) but this fails to achieve statistical significance across the three groups of carers (X^2=3.90; df=6).

When asked who or what patients and carers perceived as their main social support a significant number in the three groups identified the church (Table 69). This is further supported by a previous question regarding the importance of religious beliefs to patients and carers. In the first line group, 30 patients and 28 carers said that religious beliefs were important (75 per cent, and 70 per cent). In the follow up group, 25 patients and 28 carers (62.5 per cent and 70 per cent) answered in the same way and in the palliative group 20 patients and 22 carers (50 per cent and 55 per cent) felt religious beliefs to be important.

Table 69
Main social supports identified by patients and their carers (n=40 subjects in each group).

Main social support	First Line		Follow up		Palliative	
	Patient	Carer	Patient	Carer	Patient	Carer
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
Spouse	11(27.5)	21(52.5)	4(10)	5(12.5)	7(17.5)	3(7.5)
Family	12(30)	6(15)	5(12.5)	6(15)	10(25)	10(25)
Friend	11(27.5)	7(17.5)	17(42.5)	15(37.5)	10(25)	12(30)
Church	6(15)	6(15)	14(35)	14(35)	13(32.5)	15(37.5)

Chi square analysis reveals no statistically significant difference between the responses of the three groups of patients (X^2=11.92; df=6) but a significant difference between the groups of carers (X^2=28.65; df=6; $p<0.001$).

Patients and carers were pressed further on the issue of emotional support and were asked if in the past they had a particular person with whom they shared their worries and problems (Table 70).

Table 70
Individuals with whom patients and carers have shared worries and problems in the past (n=40 subjects in each group).

Individuals to share worries	First Line		Follow up		Palliative	
	Patient	Carer	Patient	Carer	Patient	Carer
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
No one	0(0)	0(0)	8(20)	1(2.5)	8(20)	5(12.5)
Friend	9(22.5)	3(7.5)	13(32.5)	9(22.5)	10(25)	16(40)
Spouse	26(65)	29(72.5)	18(45)	24(60)	19(47.5)	18(45)
Relative	4(10)	5(12.5)	1(2.5)	5(12.5)	3(7.5)	1(2.5)
Parent	1(2.5)	3(7.5)	0(0)	1(2.5)	0(0)	0(0)

One particularly striking aspect of the data from Table 70 is the importance of the spouse as a confidant. The majority of patients and carers report that the person with whom they shared their worries and problems in the past is the spouse. In a life-threatening illness such as cancer where the patient or carer is one's usual confidant, this sharing of fears and worries may be compromised so as not to cause distress to the other. At this time the emotional support from family and friends becomes important and, as described previously, most patients and carers report that they have access to such support (Table 68).

A series of questions was posed regarding perceived changes in the relationship between carer and patient, the amount of communication between them and the effect of the illness and its treatment on the family as a whole.

The majority of patients and carers felt that the relationship between them was closer since the diagnosis and that communication between them had increased. On the other hand, a significant number of patients and carers perceived that they had become more distant and that communication between had decreased. These latter effects were always reported accompanied by some distress on the part of the respondent. (Table 71 and 72).

Table 71
Perceived changes in the relationship between patients and carers (n=40 subjects in each group).

Perceived relationship changes	First Line		Follow up		Palliative	
	Patient	Carer	Patient	Carer	Patient	Carer
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
Closer	25(62.5)	25(62.5)	19(47.5)	24(60)	27(67.5)	28(70)
More distant	9(22.5)	8(20)	0(0)	9(22.5)	3(7.5)	0(0)
No change	6(15)	7(17.5)	21(52.5)	7(17.5)	10(25)	12(30)

Chi square analysis reveals a statistically significant difference between the three groups of patients (X^2=21.75; df=4; p<0.001) and between the three groups of carers (X^2=10.85; df=4; p<0.05).

Table 72
Perceived changes in communication between patient and carer (n=40 subjects in each group).

Perceived communication changes	First Line		Follow up		Palliative	
	Patient	Carer	Patient	Carer	Patient	Carer
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
More	25(62.5)	25(62.5)	18(45)	24(60)	25(62.5)	23(57.5)
Less	9(22.5)	7(17.5)	1(2.5)	10(25)	7(17.5)	0(0)
No change	6(15)	8(20)	21(52.5)	6(15)	8(20)	17(42.5)

Chi square analysis reveals a statistically significant difference between the three groups of patients (X^2=18.93; df= 4; p<0.001) and between the three groups of carers (X^2=16.02; df=4; p<0.01).

The two tables 71 and 72 describe the perceptions of patients and carers across the groups with respect to the relationship and communication change. It is interesting to note, for example, that in the follow up group of patients only one respondent indicates that the relationship and communication

are negatively affected, presumably because the patient is relatively well at this time.

Carers' perceptions differ at this time as 22.5 per cent and 25 per cent perceived that there are negative consequences of the illness. The carers in the palliative group, however, perceive that there are no adverse consequences of the illness and its treatment on the relationship and communication

In assessing the impact of the disease and its treatment on the family as a whole, a range of responses were given (Table 73).

Table 73
The perceived impact of the illness on the entire family: patient and carer (n= 40 subjects in each group).

Perceived impact on family	First Line		Follow up		Palliative	
	Patient	Carer	Patient	Carer	Patient	Carer
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
Brought closer	14(35)	5(12.5)	6(15)	10(25)	4(10)	3(7.5)
Caused distress	10(25)	15(37.5)	6(15)	5(12.5)	22(55)	21(52.5)
Appreciation of other person	15(37.5)	20(50)	13(32.5)	16(40)	14(35)	12(30)
Pushed further apart	1(2.5)	0(0)	2(5)	2(5)	0(0)	4(10)
No effect	0(0)	0(0)	13(32.5)	7(17.5)	0(0)	0(0)

The commonest responses of both patients and carers are that the illness has either brought the family closer together, caused emotional distress in the family or made them appreciate the other person and not take them forgranted. Not surprisingly, the majority of patients and carers in the palliative group perceive that the illness has caused significant emotional distress in the family.

The final series of questions from the brief interview schedule relate to the perceived changes outside the home with friends and relatives, the effect on leisure activities and the carers' perceptions of their role in the treatment of the illness.

Most patients and carers felt that since the illness had been diagnosed interaction outside the home with friends and relatives had either decreased or that there was no change (Tables 74 and 75). There were certain deviations from this pattern in that those patients and carers in the follow up group were more likely to report an increase in interaction outside the home. Similarly, carers in the first line treatment group were more likely to report an increase in social interaction outside the home with relatives. This is probably due to the fact that the patient had been in hospital sometimes for several days at a time receiving chemotherapy and relatives had increased their level of support and contact with the carer.

Table 74
Perceived changes in social interaction outside the home with friends (n=40 subjects in each group).

Perceived social changes	First Line		Follow up		Palliative	
	Patient	Carer	Patient	Carer	Patient	Carer
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
No change	19(47.5)	17(42.5)	18(45)	12(30)	15(37.5)	12(30)
Increase	4(10)	4(10)	11(27.5)	9(22.5)	2(5)	3(7.5)
Decrease	17(42.5)	19(47.5)	11(27.5)	19(47.5)	23(57.5)	25(62.5)

Chi square analysis across the three groups of patients reveals a significant difference between them (X^2=12.62; df=4; p<0.02). The same analysis across the three groups of carers , however, does not achieve statistical significance (X^2=6.24; df=4).

Table 75
Perceived changes in social interaction outside the home with relatives (n= 40 subjects in each group).

Change in social interaction	First Line		Follow up		Palliative	
	Patient	Carer	Patient	Carer	Patient	Carer
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
No change	14(35)	10(25)	18(45)	12(30)	13(32.5)	15(37.5)
Increase	5(12.5)	17(42.5)	6(15)	14(35)	0(0)	3(7.5)
Decrease	21(52.5)	13(32.5)	16(40)	14(35)	27(67.5)	22(55)

Chi square analysis reveals that there is no statistically significant difference between the three groups of patients (X^2=9.41; df=4), whereas the same statistical analysis between the three groups of carers does achieve statistical significance (X^2=13.59; df=4; p<0.02).

The analysis of the data from Tables 74 and 75 suggests that the illness and its treatment has a significant impact on patients' interaction with friends outside the home but not with relatives. The effect on carers is that there is a significant effect on social interaction with relatives but not with friends. The patients tend to decrease interaction with friends throughout the illness and carers to increase their interaction with relatives through the course of the illness.

Patients report a significant change through the illness in leisure interests and activities (Table 76) (X^2=12.66; df=4; p<0.02). Carers, however, do not report a significant change (X^2=5.46; df=4). The majority of carers in all three groups report a decrease in the time that they have given to their leisure activities.

Table 76
Perceived changes in leisure activities of patients and carers through the illness (n=40 subjects in each group).

Leisure activities	First Line		Follow up		Palliative	
	Patient	Carer	Patient	Carer	Patient	Carer
	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)
No change	11(27.5)	11(27.5)	19(47.5)	12(30)	21(52.5)	8(20)
Increase	29(72.5)	29(72.5)	18(45)	26(65)	19(47.5)	32(80)
Decrease	0(0)	0(0)	3(7.5)	2(5)	0(0)	0(0)

The majority of both patients and carers report either no change in their leisure activities or a decrease, very few report an increase. The only group where patients and carers reported any increase was in the follow up group.

Only the primary carer was asked how they perceived their role in the treatment of the disease (Table 77).

Table 77
The primary carers perception of their role in the treatment of the disease (n= 40 subjects in each group).

Role	First Line	Follow up	Palliative
	n (%)	n (%)	n (%)
No role	0 (0)	1 (2.5)	3 (7.5)
Support	6 (15)	9 (22.5)	15 (37.5)
Help come to terms with the illness	12 (30)	12 (30)	17 (42.5)
Help fight disease	22 (55)	18 (45)	5 (12.5)

Chi square analysis reveals a statistically significant difference between the three groups (X^2=19.45; df=6; $p<0.01$). There is a clear change in the perception of the carers role across the three groups. In the first line group and the follow up group the majority of carers report their role to be to help the patient fight the disease. In the palliative group, however, the carers are divided between supporting the patient and helping them come to terms with the illness. Interestingly, very few carers feel that they have no role to play in the illness.

The data from the brief interview schedule augments data from some of the other assessment tools used e.g. the Psychological Adjustment to Illness Scale. This data aids the understanding of the impact of the illness and its treatment on the lives of patients and their carers.

Variables contributing to anxiety and depression scores in patients and their primary carers

First line management group

The variables contributing to anxiety and depression in patients and their carers were further examined using an automated stepwise multiple regression analysis, with alpha to enter at the 0.05 level of significance and alpha to remove 0.1 [Dillon and Goldstein, 1984]. All the variables assessed were entered including data from the brief interview schedule (coding the latter as dummy variables, as described by Armitage and Berry, 1987). The dependent variables for patients receiving first line chemotherapy were anxiety and depression scores from the Hospital Anxiety and Depression Scale. Four variables emerged from this analysis as contributing to the patients' anxiety score (Table 78).

Table 78
Stepwise multiple regression analysis using patients' anxiety (HAD) score as the dependent variable.

Step	Variable entered	Beta	r	Contribution to R^2	Cumulative R^2
1	HAD (anx): carer	.398	.450	.203	.203
2	Had (dep): carer	.441	.598	.155	.358
3	Performance Status	.371	.668	.088	.446
4	P.S.S.from friends (carer)	.340	.714	.064	.510

(P.S.S.= Perceived Social Support)

The four variables significantly associated with anxiety in the patient were the HAD anxiety and depression scores of the carer, the performance status of the patient, and the carers' perceived social support from friends. These four variables explained 51 per cent of the variance of the independent variable and in combination produced a significant association ($F=9.11$; $df=4, 35$; $p<0.001$). High levels of distress in the carer, poorer performance status and higher perceived social support from friends on the part of the carer were associated with elevated anxiety levels in the patient.

An automated stepwise procedure using the same levels of inclusion and exclusion was performed using the patients' HAD depression score as the dependent variable (Table 79),

Table 79
Stepwise multiple regression analysis using patients' HAD depression score as the dependent variable.

Step	Variable entered	Beta	r	Contribution to R^2	Cumulative R^2
1	HAD (anx): carer	.284	.414	.172	.172

In the latter analysis only the carers' HAD anxiety score emerged as contributing significantly to the patients' HAD depression score ($F=7.88$; $df=1, 38$; $p<0.01$). This single variable, however, only explains 17.20 per cent of the variance of the patients' depression score.

Automated stepwise regression analysis was then utilised to examine the contribution of variables to HAD anxiety and depression scores in the carers (Table 80 and 81).

Table 80
Stepwise multiple regression analysis using carers' HAD anxiety as the dependent variable.

Step	Variable entered	Beta	r	Contribution to R^2	Cumulative R^2
1	HAD (anx): patient	.510	.450	.203	.203
2	Performance Status	.434	.594	.150	.353
3	P.S.S. from family(carer)	.355	.659	.081	.434

(P.S.S. = Perceived Social Support)

Table 81
Stepwise multiple regression analysis using carers' HAD depression as the dependent variable.

Step	Variable entered	Beta	r	Contribution to R^2	Cumulative R^2
1	P.S.S.from family (carer)	.209	.314	.099	.099

(P.S.S.= perceived social support)

The stepwise analysis of the carers' anxiety score produced three variables which significantly contributed to it. These variables were: the HAD anxiety score of the patient; the performance status; and the carers' perceived level of social support from the family. These variables in combination explained 43.40 per cent of the variance of the dependent variable ($F= 9.22$; $df=3, 36$; $P<0.001$). In examining the contribution of variables to the carers' HAD depression score, however, only one emerged, namely the carers' perceived social support from the family. This single variable was only

able to explain 9.90 per cent of the variance of the dependent variable ($F= 4.15$; $df = 1, 38$; $p<0.05$).

Clearly, in examining the combined contribution of variables to the anxiety and depression scores of patients and their carers several factors emerge. The psychological state of the "significant other" (patient or carer), the patients' performance status, and the carers' perceived emotional social support emerge in explaining the relevant dependent variable, particularly patient anxiety and anxiety in the carer. The variables which contribute to distress are similar in both patient and carer.

Follow up surveillance

The same automated stepwise regression analysis was performed on the HAD anxiety and depression scores of patients in the follow up group (Table 82 and 83).

Table 82
Stepwise multiple regression analysis using patients' anxiety scores (HAD) as the dependent variable.

Step	Variable entered	Beta	r	Contribution to R^2	Cumulative R^2
1	HAD (anx): carer	.357	.375	.141	.141
2	PAIS(Total) :patient	.394	.523	.133	.274

Table 83
Stepwise multiple regression analysis using the HAD depression scores of the patient as the dependent variable.

Step	Variable entered	Beta	r	Contribution to R^2	Cumulative R^2
1	PAIS(Total) patient	.224	.427	.237	.237
2	Severity of symptoms	.379	.589	.110	.347
3	HAD (anx): carer	.324	.644	.068	.415
4	Number of symptoms	.336	.694	.066	.481

The stepwise analysis of the patients' anxiety score produced two emergent variables which produced a significant combined association. These variables were the HAD anxiety score of the carer and the total score of the patient on the Psychological Adjustment to Illness Scale (PAIS). These two variables explained 27.4 per cent of the variance of the dependent variable ($F = 6.98$; $df = 2, 37$; $p < 0.01$).

The stepwise regression analysis of the patients' depression score produced four variables explaining 48.1 per cent of the variance of the dependent variable ($F = 8.12$; $df = 4, 35$; $p < 0.001$). The four variables were the patients' total score on the PAIS, the number of symptoms and severity of these symptoms, and the HAD anxiety score of the carer.

An automated stepwise regression analysis was then performed on the HAD anxiety and depression scores of the carers of the group (Tables 84 and 85).

Table 84
Stepwise multiple regression analysis using the HAD anxiety score of the carer as the dependent variable.

Step	Variable entered	Beta	r	Contribution to R^2	Cumulative R^2
1	PAIS(Total): carer	.142	.431	.186	.186
2	HAD (anx): patient	.389	.556	.123	.309
3	Extraversion: carer	-.370	-.635	.095	.404
4	P.S.S. from friends:patien t	.416	.712	.103	.507
5	Severity of symptoms	.373	.759	.069	.576

(P.S.S.= Perceived Social Support)

Table 85
Stepwise multiple regression analysis using the HAD depression score of the carer as the dependent variable.

Step	Variable entered	Beta	r	Contribution to R^2	Cumulative R^2
1	P.S.S. from friends: patient	.271	.472	.223	.223

(P.S.S.= Perceived Social Support)

The stepwise regression analysis of the carers' HAD anxiety score produces five variables that contribute significantly in combination ($F=9.22$; df= 5, 34; $p<0.001$). The five variables are the carers' total score on the PAIS, the HAD anxiety score of the patient, the Eysenck Personality Inventory (EPI) extraversion score of the carer (negative beta indicates lower scores i.e. introversion), the patients' perceived social support from friends and the severity of the patients' symptoms. These five variables account for 57.6 per cent of the variance of the dependent variable.

The stepwise regression analysis of the carers' HAD depression score, on the other hand, only produces a single variable which contributes significantly ($F=10.89$; $df=1, 38$; $p<0.01$). The single variable is the patients' perceived social support from friends and this explains 22.3 per cent of the variance of the dependent variable.

Once again in explaining the variance associated with distress in patients and their carers the presence of anxiety or depression in the other assumes importance. For the patient the number of symptoms and their severity are implicated along with the global adjustment to illness. In the case of the carer, however, symptom severity, aspects of their own personality and the presence of social support from friends may contribute to the distress.

Palliative therapy group

Finally, the HAD anxiety scores of the patients were subjected to a stepwise multiple regression analysis. The results of this analysis are shown in Table 86.

Table 86
Stepwise multiple regression analysis using patient anxiety as the dependent variable.

Step	Variable entered	Beta	r	Contribution to R^2	Cumulative R^2
1	Extraversion: carer	-.731	-.390	.152	.152
2	HAD (anx): carer	.353	.507	.105	.257
3	Performance Status	.368	.598	.101	.358
4	P.S.S. from friends:patient	.456	.701	.133	.491
5	P.S.S.from family:patient	.429	.765	.094	.585
6	Number of symptoms	.405	.808	.068	.653
7	Age of patient	-.357	-.835	.044	.697

(P.S.S.= Perceived Social Support)

A stepwise multiple regression analysis using the patients' HAD depression score was also performed. In this analysis no variables were able to be entered as the amount of variance explained by each alone or in combination was not sufficient to achieve statistical significance.

The stepwise analysis using the patients' anxiety score as the dependent variable revealed seven variables. These variables in combination accounted for 69.7 per cent of the variance of the patients' anxiety score ($F= 10.53$; $df=7, 32$; $p<0.001$). The seven variables included the extraversion score of the carer from the EPI (negative Beta value indicates lower scores i.e. introversion), the HAD anxiety subscale, the patients' performance status, the patients' perceived social support from family and friends, the number of symptoms reported by the patient and the age of the patient (negative Beta value indicates younger patients). Again, the psychological state of

the carer plays a significant role in contributing to the psychological state of the patient.

The HAD anxiety and depression scores of the carer were also subjected to a stepwise multiple regression analysis (Tables 87 and 88).

Table 87
Stepwise multiple regression analysis using the HAD anxiety score of the carer as the dependent variable.

Step	Variable entered	Beta	r	Contribution to R^2	Cumulative R^2
1	PAIS(Total): carer	.205	.429	.184	.184

Table 88
Stepwise multiple regression analysis using the HAD depression scores of the carer as the dependent variable.

Step	Variable entered	Beta	r	Contribution to R^2	Cumulative R^2
1	P.S.S. from friends:patient	.266	.337	.114	.114
2	PAIS(Total): patient	.344	.468	.105	.219
3	Neuroticism: carer	.321	.547	.080	.299

(P.S.S.= Perceived Social Support)

The stepwise analysis of the carers' anxiety scores shows that only one variable emerges, explaining 18.4 per cent of the variance. This single variable is the PAIS total score of the carer ($F=8.55$; $df=1, 38$; $p<0.01$).

The stepwise analysis of the carers' depression scores, however, produced three variables explaining 29.9 per cent of the variance. These three variables included the patients'

perceived social support from friends, the PAIS score total from the patient and the carers' neuroticism score from the EPI ($F=5.13$; $df=3, 36$; $p<0.01$).

Conclusions from stepwise multiple regression analysis in the three groups of patients and their carers.

The stepwise regression analysis across the three groups of patients and their carers demonstrates a number of important factors. In the analysis of the patients' HAD anxiety score, the carers' psychological state makes an important contribution. In the first line group of patients, the carers' anxiety and depression score account for 20.3 per cent and 15.5 per cent of the variance respectively. In this group, performance status accounts for 8.8 per cent and the carers' perceived social support from friends account for 6.4 per cent.

In the follow up surveillance group of patients the anxiety of the carer accounts for 14.1 per cent of the variance and the patients' total score of the PAIS scale accounts for 13.3 per cent. This latter variable represents the global impact of the illness and its treatment on the patients' life. In this analysis, a higher score is associated with higher levels of anxiety. Interestingly, in this group physical symptoms and social support fail to achieve statistical significance and thus are not entered into the regression analysis.

In the group of patients receiving palliative therapy (anxiety score) the carers' anxiety score contributes 10.5 per cent.

Performance status contributes 10.1 per cent and the number of symptoms 6.8 per cent. The patients' perceived social support from friends and from family contribute 13.3 per cent and 9.4 per cent. In addition, however, aspects of the carers' personality (lower extraversion score) contribute 15.2 per cent and the patients' age 4.4 per cent. One hypothesis regarding the contribution of the carers' personality type to the patients' anxiety is that the more introverted carers (i.e. those with the lower extraversion scores) may show their distress more than those who are extraverted and therefore are able to disguise their distress. The more introverted carers therefore may appear to be more anxious and/or depressed which in turn effects the patient.

These combinations of variables account for 51 per cent of the variance of the patients' anxiety score in the first line group and almost 70 per cent in the palliative group (69.7 per cent). In the follow up group, however, they account for less than a third (27.4 per cent) and may, therefore, be considerably less important.

The carers' anxiety score, when subjected to the same analysis, reveals different clusters of variables. In the first line group the variables contributing to the anxiety score are similar to those of the patient. The patients' anxiety accounts for 20.3 per cent of the variance, performance status 15 per cent and the carers' perceived social support from family 8.1 per cent.

In the follow up group (of carers) a completely different picture to that of the patient emerges. The carers' total score on the PAIS accounts for 18.6 per cent and the patients' anxiety score 12.3 per cent. These are similar to those found in the patient group at the same stage of treatment. In addition, however, the carers' own extraversion score (lower score is equivalent to introversion) accounts for 9.5 per cent, their perceived social support from friends accounts for 10.3 per cent and the severity of symptoms 6.9 per cent of the variance. These results suggest that the relationship of a number of variables to dependent variables such as anxiety may be complex and that trait and state factors in both patients and carers such as aspects of personality, symptomatology and social support may interact with a number of other factors to explain anxiety.

In the palliative therapy group of carers only one factor, the carers' PAIS total score, emerged, explaining 18.4 per cent of the variance. This is in contrast to the cluster of variables found in the patient group. The PAIS total score reflects the fact that those carers whose lives are the most severely affected experience the greatest anxiety. This one variable, however, only accounts for 18.4 per cent of the variance compared to the cluster of variables in the other two groups where they account for 43.4 per cent in the first line group and 57.6 per cent in the follow up group.

This series of analyses demonstrate the importance of the psychological state of the significant other, physical symptoms

and performance status, social support from family and friends, the impact of the illness on lifestyle and specific personality factors.

When the depression scores of patients and their carers are used as the dependent variable a different set of variables emerge although the variance in this case is not explained so satisfactorily using stepwise multiple regression analysis. In the first line group of patients only 17.2 per cent of the variance is satisfactorily explained by a single variable: the anxiety score of the carer. In the first line group of carers only 9.9 per cent of the variance is explained by a single variable: the carers' perceived social support from family. The variance explained in these two groups is so small as to be of very little significance.

In the follow up group of patients 48.1 per cent of the variance is explained by four variables: the patients' PAIS total score (23.7 per cent); the number of symptoms (6.6 per cent); the severity of the symptoms (11 per cent); and the anxiety of the carer (6.8 per cent). This is a more significant explanation of the variance in this group. In the carers' group only 22.3 per cent of the variance is explained by a single variable, the patients' perceived social support from friends.

In the palliative therapy group of patients, no variables were entered into the stepwise analysis as none of the partial correlations achieved the required level of significance for inclusion. An option to overcome this would have been to

"force" variables into the equation but this would only have explained extremely small amounts of the variance and would, therefore, have had very little importance. In the group of carers, however, 29.9 per cent of the variance was explained by the patients' perceived social support from friends (11.4 per cent), the patients' PAIS total score (10.5 per cent) and the carers' neuroticism score (8.0 per cent). These stepwise analyses again demonstrate the importance of variables related to "significant other" in the explanation of patients' or carers' psychological state. The results show that the anxiety scores are explained more successfully than those of depression.

Stepwise multiple regression analysis and the carers' General Health Questionnaire Score (GHQ).

An additional measure of distress in the carer that was collected was the General Health Questionnaire (GHQ) score. As described earlier, this is a global measure of distress covering four subscales. An automated stepwise regression analysis was carried out using this score as the dependent variable in all three groups of carers (Tables 89, 90, and 91).

Table 89
Stepwise multiple regression analysis using the carers' GHQ score as the dependent variable (first line group).

Step	Variable entered	Beta	r	Contribution to R^2	Cumulative R^2
1	HAD (dep): patient	.643	.488	.238	.238
2	Extraversion: carer	-.391	-.596	.117	.355

Table 90
Stepwise multiple regression analysis using the carers' GHQ score as the dependent variable (follow up surveillance group).

Step	Variable entered	Beta	r	Contribution to R^2	Cumulative R^2
1	PAIS(Total); carer	.117	.604	.365	.365
2	Age: carer	-.342	-.663	.074	.439

Table 91
Stepwise multiple regression analysis using the carers' GHQ score as the dependent variable (palliative therapy group).

Step	Variable entered	Beta	r	Contribution to R^2	Cumulative R^2
1	HAD (anx): patient	.293	.418	.175	.175
2	PAIS(Total): carer	.428	.571	.151	.326

The stepwise analysis of the first line group reveals that two variables emerge explaining 35.5 per cent of the variance. The two variables are the HAD depression score of the patient which explains 23.8 per cent of the variance and the extraversion score (the negative Beta value indicates that it is introversion) of the carer from the EPI which explains 11.7

per cent of the variance (F= 10.17; df=2, 37; p<0.001). This suggests that those carers who tend to be less extraverted but look after patients who are more depressed tend to be more distressed.

In contrast, the stepwise analysis of the follow up group revealed two different variables explaining 43.9 per cent of the variance. The two variable are the PAIS (total) score of the carer which explains 36.5 per cent of the variance and the (younger) age of the carer which explains 7.4 per cent (F= 10.17; df= 2, 37; p<0.001). This suggests that those carers who have higher PAIS total scores but who are younger (Beta value = -.342) have a higher level of distress.

The palliative therapy group present a different picture again. Two variables emerge explaining 32.6 per cent of the variance. These two variables are the HAD anxiety score of the patient which explains 17.5 per cent of the variance and the PAIS total score of the carer which explains 15.1 per cent (F=9.95; df= 2, 37; p<0.001).

In explaining the GHQ score, the psychological state of the significant other, the PAIS score of the carer, age of the carer and specific personality characteristics of the carer are implicated. The perceived social support from family and friends of patients and carers and the number and severity of patients' symptoms fail to contribute significantly to the regression analysis. Clearly, therefore the HAD scale and the GHQ are not assessing exactly the same phenomenon but

represent different aspects of distress explained by different variables. The contribution of the "significant others'" psychological state is implicated in the explanation of both scales.

Reduction of the data: factor analysis

The present study has examined a large number of variables in three groups of patients with lung cancer and their carers.

One way of reducing these data sets and therefore exploring the possible underlying structure and interrelationships between variables is to embark on a factor analysis [Child, 1990].

The variables for each group of patients and their carers were subjected to a factor analysis and the optimum explanation of the variance obtained. Only the standardised questionnaire data were entered into the factor analysis and certain demographic data. The Brief Interview Schedule data were not included due to its descriptive nature and due to th lack of independent validation of it.

Factor analysis: first line group of patients and carers

The data from the first line group of patients and carers are shown in Table 92 and 93. The number of factors was restricted to those factors having an eigenvalue of one or greater than one. The data are shown as an unrotated factor matrix (Table 92) and then are subjected to an orthogonal, varimax rotation thus producing factors which are independent of each other (Table 93).

Table 92
Unrotated factor matrix of variables associated with the first line management group, including eigenvalues and the percentage of variance explained by each.

Variable	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7
Patients' age	-0.26	0.15	0.65	0.22	0.31	0.01	-0.39
Carers' age	-0.32	0.61	0.75	0.19	0.20	-0.06	-0.33
Anx(patient)	0.51	-0.15	0.07	0.57	-0.44	-0.14	0.09
Anx (carer)	0.64	-0.52	0.09	0.20	0.18	0.30	0.11
Dep (patient)	0.55	-0.27	0.21	0.45	-0.44	-0.13	-0.08
Dep (carer)	0.55	-0.20	0.17	-0.17	0.24	0.62	0.03
Family Supp. (patient)	0.57	0.34	0.23	0.29	0.32	-0.21	0.12
Family Supp. (carer)	0.64	-0.11	-0.13	0.12	0.40	-0.10	-0.18
Friends Supp (patient)	0.35	0.54	0.02	0.07	0.31	-0.48	0.17
Friends Supp. (carer)	0.54	0.20	0.15	0.03	-0.08	-0.10	0.01
Symptom number	0.25	0.87	-0.03	-0.07	-0.04	0.17	0.22
Symptom severity	0.12	0.90	0.03	-0.05	-0.06	0.21	0.15
PAIS(Total) (Patient)	-0.39	-0.22	0.13	0.63	0.03	0.18	0.34
PAIS(Total) (Carer)	0.21	0.08	0.42	-0.27	-0.17	0.37	0.16
Extraversion (Patient)	-0.11	0.33	-0.51	0.52	0.02	0.34	-0.18
Neuroticism (Patient)	0.37	0.11	0.52	-0.35	-0.21	0.08	-0.36
Extraversion (Carer)	0.23	-0.09	-0.64	0.11	0.48	0.10	-0.31
Neuroticism (Carer)	-0.48	0.08	0.40	0.41	0.29	0.15	0.33
Performance Status	0.12	-0.53	0.21	-0.40	0.35	-0.21	0.46
EIGENVALUE	3.33	2.94	2.51	2.00	1.51	1.26	1.16
VARIANCE EXPLAINED (%)	17.55	15.48	13.22	10.53	7.93	6.64	6.10

Total variance explained = 77.45 per cent

Table 93
Varimax rotated factor matrix: first line management group.

Variable	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7
Patients' age	-.08	-0.00	***-0.89***	-0.20	0.08	-0.00	-0.11
Carers' age	-0.01	-0.05	***-0.90***	0.14	-0.01	-0.08	-0.14
Anx(patient)	***0.89***	-0.02	0.11	-0.05	0.13	0.05	-0.09
Anx (carer)	0.37	-0.29	0.13	0.03	0.17	***0.78***	-0.07
Dep (patient)	***0.89***	-0.13	-0.02	0.03	0.07	0.13	0.08
Dep (carer)	0.00	0.09	0.01	0.05	0.02	***0.91***	0.12
FamilySupp. (patient)	0.26	0.24	-0.15	0.01	***0.75***	0.17	-0.03
Family Supp. (carer)	0.14	-0.23	0.06	-0.22	***0.57***	0.39	0.23
FriendsSupp. (patient)	-0.01	0.30	0.01	0.05	***0.80***	-0.21	0.06
Friends Supp. (carer)	0.34	0.24	0.01	0.09	0.33	0.15	0.24
Symptom number	-0.07	***0.89***	0.10	-0.10	0.29	-0.01	0.07
Symptom severity	-0.10	***0.91***	-0.02	-0.12	0.19	-0.06	0.04
PAIS(Total) (Patient)	0.17	-0.12	-0.12	-0.08	-0.17	-0.01	***-0.82***
PAIS(Total) (Carer)	0.07	0.37	-0.12	0.37	-0.19	0.39	0.09
Extraversion (Patient)	0.02	0.23	0.10	***-0.82***	-0.60	-0.05	-0.23
Neuroticism (Patient)	0.19	0.22	-0.39	0.29	-0.06	0.24	***0.58***
Extraversion (Carer)	-0.23	-0.30	0.25	***-0.66***	0.29	0.24	0.15
Neuroticism (Carer)	-0.14	0.10	-0.41	0.09	-0.00	-0.02	***-0.77***
Performance Status	-0.23	-0.42	0.19	***0.68***	0.22	0.28	-0.10

(Italicised figures = most significant factor loading variables per factor)

The eigenvalues, percentage of variance explained by each factor and the cumulative variance for the related factor matrix are shown in Table 94. The criterion for item selection was those variables with a loading of 0.6. Table 94 is included to show more clearly the seven factors, their eigenvalues and the variances they account for. This table is necessary to interprest accurately Table 93 as it provides the values resulting from each factor in this latter table. Table 94 can then be linked to Table 95 to show how the factors have been named. Table 94 is essential as it describes the importance of each factor alone and in combination with others.

Table 94
Factor eigenvalues, percentage of variance explained by each factor and the cumulative variance for the rotated factor matrix (first line group).

Factor	Eigenvalue	Percentage of variance	Cumulative variance (%)
1	2.16	11.35	11.35
2	2.54	13.35	24.70
3	2.13	11.22	35.92
4	1.93	10.14	46.06
5	2.02	10.66	56.72
6	2.06	10.85	67.57
7	1.88	9.88	77.45

The factor analysis of these variables have produced seven principle factors accounting for 77.45 per cent of the total variance. An examination of the rotated factor matrix shows the factor loadings. Variables loading most highly on factor one are the HAD anxiety and depression scores of the patient. This factor, therefore, represents a measure of patient distress. The two variables loading most highly on factor two are the number of symptoms and their severity. This factor therefore represents the symptomatology of the patient. Interestingly, performance status does not load significantly on this factor. Factor three is a general age factor as the two variables loading most highly are age of the patients and age of the carer. Factor four is a factor represented by the extraversion scores of the patient and the carer on the EPI, and performance status. This factor probably represents a measure of "sociability of the family" as the personality variables of patient and carer and the physical state of the patient as

assessed by performance status indicate the potential to socialise as a family unit.

Factor five represents a general measure of social support as three of the four social support subscales load on it (perceived social support from family and friends as perceived by the patient and social support from family as perceived by the carer). Factor six represents a measure of carer distress as the two variables loading on it are the HAD anxiety and depression of the carer. Factor seven is represented by the neuroticism scores of the patient and carer (from the EPI) and the patients' PAIS total score. As neuroticism from the EPI can be equated with anxiety [McGuire et al., 1963] this may represent a general measure of adjustment to illness on the part of the patient.

These seven factors represent a considerable degree of reduction of redundancy in explaining almost 75 per cent of the variance of the data from an initial large pool of variables (Table 95).

Table 95
Factors derived from the rotated factor matrix and the variance explained: first line management.

Factor Name	Variance explained (%)
1. Patient distress	11.35
2. Symptomatology	13.35
3. Age	11.22
4. Sociability of the family	10.14
5. Perceived social support	10.66
6. Carer distress	10.85
7. Neuroticism and patient adjustment to illness	9.88

The variables from the follow up surveillance group were then subjected to the same statistical approach.

Factor analysis: follow up surveillance group

Factor analysis of the variables from the follow up group revealed a different factor structure. The unrotated and rotated factor matrices are shown in Tables 96 and 97.

Table 96
Unrotated factor matrix of variables associated with the follow up surveillance group, including eigenvalues and the percentage of variance explained by each.

Variable	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8
Patients' age	-0.53	0.11	-0.21	-0.05	0.74	0.04	-0.01	0.07
Carers' age	-0.54	-0.10	-0.38	-0.60	0.65	0.02	-0.20	0.07
Anx(patient)	0.33	-0.74	0.25	0.08	0.09	-0.05	0.24	0.17
Anx (carer)	0.55	-0.05	0.25	0.57	0.29	-0.10	-0.21	0.13
Dep (patient)	0.34	-0.76	0.15	-0.12	0.20	-0.10	0.24	0.19
Dep (carer)	0.61	0.32	0.26	0.20	0.10	0.02	-0.31	-0.02
Family Supp. (patient)	0.67	0.16	-0.22	-0.46	0.09	0.09	-0.20	0.32
Family Supp. (carer)	0.68	0.24	-0.22	-0.45	0.21	0.10	-0.12	0.32
FriendsSupp. (patient)	0.67	0.38	0.02	0.00	0.17	0.06	0.22	-0.19
Friends Supp. (carer)	0.58	0.34	0.13	0.10	0.15	0.26	0.48	-0.17
Symptom number	-0.30	0.25	0.75	0.11	0.19	0.33	0.06	0.10
Symptom severity	-0.35	0.32	0.77	0.11	0.12	0.24	-0.09	0.19
PAIS(Total) (Patient)	0.03	-0.47	0.46	-0.26	0.09	-0.17	0.11	0.25
PAIS(Total) (Carer)	0.41	0.02	0.07	0.22	0.34	-0.49	-0.19	-0.33
Extraversion (Patient)	-0.06	0.52	0.24	-0.19	0.06	-0.57	0.28	0.03
Neuroticism (Patient)	0.13	-0.10	-0.43	0.45	0.09	0.52	0.32	0.10
Extraversion (Carer)	0.03	-0.31	0.19	-0.41	0.36	0.13	0.15	-0.63
Neuroticism (Carer)	-0.28	0.49	-0.11	-0.10	0.08	-0.27	0.53	0.26
Performance Status	-0.04	-0.05	-0.30	0.71	0.08	-0.29	0.12	0.13
EIGENVALUE	3.67	2.61	2.26	1.87	1.54	1.32	1.20	1.10
VARIANCE EXPLAINED (%)	19.31	13.77	11.88	9.86	8.11	6.94	6.30	5.75

(Total variance explained = 81.92 per cent)

Table 97
Varimax rotated factor matrix: follow up surveillance group.

Variable	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8
Patients' age	-0.05	-0.10	-0.14	0.06	***-0.91***	0.14	0.02	0.06
Carers' age	-0.09	-0.08	0.07	0.07	***-0.93***	-0.08	-0.14	0.01
Anx(patient)	0.10	***0.86***	0.07	0.06	0.13	-0.19	0.10	0.00
Anx (carer)	***0.76***	0.23	-0.17	-0.09	0.07	-0.19	0.19	-0.31
Dep (patient)	0.05	***0.90***	0.17	-0.08	0.00	-0.13	0.05	0.09
Dep (carer)	***0.62***	-0.14	-0.22	-0.37	0.27	-0.10	0.11	-0.06
Family Supp. (patient)	0.08	0.04	0.18	***-0.92***	0.09	-0.03	0.05	-0.01
Family Supp. (carer)	0.11	0.30	0.14	***-0.94***	0.00	0.05	0.16	0.01
FriendsSupp. (patient)	0.39	-0.10	0.03	-0.40	0.24	0.19	***0.53***	0.19
Friends Supp. (carer)	0.21	-0.04	-0.04	-0.24	0.23	0.17	***0.78***	0.16
Symptom number	-0.01	0.01	***-0.92***	0.16	-0.04	0.07	0.20	0.09
Symptom severity	0.01	-0.06	***-0.95***	0.18	-0.02	0.09	-0.12	-0.03
PAIS(Total) (Patient)	-0.04	***0.69***	-0.19	0.03	0.05	0.08	-0.26	0.11
PAIS(Total) (Carer)	***0.80***	0.05	0.21	0.02	-0.02	0.11	-0.19	0.13
Extraversion (Patient)	0.15	-0.10	-0.11	-0.03	0.07	***0.84***	-0.12	0.04
Neuroticism (Patient)	-0.14	0.01	0.14	0.07	-0.15	-0.35	0.12	-0.3
Extraversion (Carer)	0.05	0.22	0.03	0.09	-0.14	-0.08	0.09	***0.88***
Neuroticism (Carer)	-0.26	-0.13	-0.04	0.02	-0.18	***0.77***	0.17	-0.19
Performance Status	0.29	0.03	0.25	0.40	-0.17	0.05	0.21	***-0.58***

(Italicised figures= most significant factor loading variables per factor)

The eigenvalues and percentage of variance explained by each factor is shown in Table 98.

Table 98
Factor eigenvalues, percentage of variance explained by each factor and the cumulative variance for the rotated factor matrix (follow up group).

Factor	Eigenvalue	Percentage of variance	Cumulative variance (%)
1	2.06	10.83	10.83
2	2.22	11.70	22.53
3	2.12	11.18	33.71
4	2.31	12.15	45.86
5	2.04	10.76	56.62
6	1.66	8.72	65.34
7	1.70	8.94	74.28
8	1.45	7.64	81.92

The factor analysis of this data set produced eight principle factors accounting for 81.92 per cent of the total variance. The variables loading most significantly on factor one are: carers' HAD anxiety and depression scores; and the carers' PAIS total score. This factor, therefore, represents carer distress and adaptation to illness. Factor two loads most heavily on the patients' HAD anxiety and depression score and the patients' total PAIS score. This factor represents patient distress and adaptation to illness. Factor three loads most heavily on the number and severity of the patients' symptoms and therefore represents general symptomatology. Factor four loads most heavily on patients' and carers' perceived social support from family and therefore represents a general measure of family support. Factor five represents a measure of age as it loads on the ages of patients and carers. Factor six loads on the EPI extraversion score of the patient and the neuroticism score of the carer and could therefore be viewed as a measure of "family personality". Factor seven loads on patients' and

carers' perceived social support from friends and therefore represents a measure of social support from friends. Factor eight loads on the carers' extraversion score of the EPI and performance status and therefore represents a "sociability" factor as the performance status scale assesses the patients' ability of carry out certain daily tasks and the personality variable assesses how outgoing a person is generally.

These eight variables and the variance that they represent are shown in Table 99.

Table 99
Factors derived from rotated factor matrix and the variance explained: follow up group.

Factor Name	Variance explained (%)
1. Carer distress and adaptation to illness.	10.83
2. Patient distress and adaptation to illness.	11.70
3. Symptomatology	11.18
4. Support from family.	12.15
5. Age.	10.76
6. Family personality.	8.72
7. Support from friends.	8.94
8. Sociability.	7.64

Factor analysis: palliative therapy group

Factor analysis of the data from the palliative therapy group again revealed seven factors but with a different structure again. The unrotated and rotated factor matrices are shown in Tables 100 and 101.

Table 100
Unrotated factor matrix of variables associated with the palliative therapy group, including eigenvalues and the percentage of variance explained by each.

Variable	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7
Patients' age	-0.32	0.44	0.22	0.08	0.49	0.33	-0.05
Carers' age	-0.50	0.13	0.29	0.47	0.33	0.25	0.07
Anx(patient)	0.48	0.41	0.05	0.34	-0.37	-0.19	-0.34
Anx (carer)	0.53	-0.36	0.59	0.25	-0.02	0.06	0.03
Dep (patient)	0.19	0.10	0.03	0.36	0.07	0.29	-0.62
Dep (carer)	0.45	-0.40	0.37	0.37	-0.01	-0.10	0.21
FamilySupp. (patient)	0.80	-0.13	-0.18	0.02	0.36	0.07	-0.22
Family Supp. (carer)	0.80	-0.13	-0.19	-0.07	0.27	0.13	-0.28
FriendsSupp. (patient)	0.61	-0.39	-0.19	-0.08	0.04	0.34	0.36
Friends Supp. (carer)	0.62	0.01	-0.43	-0.20	0.03	0.20	0.21
Symptom number	0.46	0.64	0.38	-0.22	-0.07	0.19	0.05
Symptom severity	0.31	0.75	0.34	-0.25	0.01	0.14	0.25
PAIS(Total) (Patient)	0.44	0.32	0.19	0.12	-0.01	-0.60	0.12
PAIS(Total) (Carer)	0.27	-0.17	0.44	0.25	0.09	-0.08	0.27
Extraversion (Patient)	-0.31	-0.11	0.39	-0.23	-0.46	0.44	-0.13
Neuroticism (Patient)	-0.11	0.15	-0.38	0.60	0.21	-0.02	0.08
Extraversion (Carer)	0.01	0.32	-0.36	0.37	-0.10	0.28	0.47
Neuroticism (Carer)	-0.35	-0.48	0.34	-0.06	0.02	0.19	-0.00
Performance Status	-0.03	-0.04	0.25	-0.44	0.69	-0.25	0.00
EIGENVALUE	3.86	2.36	1.99	1.73	1.46	1.29	1.25
VARIANCE EXPLAINED (%)	20.33	12.41	10.49	9.09	7.68	6.78	6.58

Total variance explained = 73.36 per cent

Table 101
Varimax rotated factor matrix: palliative therapy group.

Variable	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7
Patients' age	-0.29	0.45	-0.13	0.32	0.27	-0.39	0.25
Carers' age	-0.53	0.11	0.17	0.29	0.15	-0.36	0.19
Anx(patient)	0.03	0.23	0.11	0.02	-0.33	0.26	***0.66***
Anx (carer)	0.16	0.05	***0.84***	0.25	0.17	0.18	0.18
Dep (patient)	0.05	0.01	0.02	-0.05	-0.19	-0.12	***0.80***
Dep (carer)	0.16	-0.12	***0.80***	0.02	-0.14	0.19	0.00
FamilySupp. (patient)	***0.77***	0.02	0.21	-0.07	0.24	0.27	0.37
Family Supp. (carer)	***0.79***	0.03	0.14	0.04	0.18	0.26	0.19
FriendsSupp. (patient)	***0.78***	-0.01	0.32	0.03	-0.16	-0.20	-0.18
Friends Supp. (carer)	***0.79***	0.15	-0.07	-0.07	-0.13	0.09	-0.11
Symptom number	0.14	***0.87***	0.07	0.18	-0.12	0.20	0.12
Symptom severity	0.04	***0.94***	-0.01	0.04	0.03	0.17	-0.08
PAIS(Total) (Patient)	0.00	0.25	0.30	-0.12	0.16	***0.73***	-0.09
PAIS(Total) (Carer)	-0.02	0.08	***0.69***	-0.09	0.03	0.03	-0.04
Extraversion (Patient)	-0.09	0.18	0.07	***0.63***	-0.32	-0.29	0.10
Neuroticism (Patient)	-0.06	-0.15	-0.02	***-0.72***	-0.16	0.03	0.15
Extraversion (Carer)	0.11	0.23	-0.06	***-0.56***	-0.06	-0.19	-0.17
Neuroticism (Carer)	-0.25	-0.25	-0.21	***-0.42***	0.09	-0.32	-0.06
Performance Status	0.03	0.01	0.00	0.04	***0.87***	-0.08	-0.14

(Italicised figures = most significant factor loadings for each factor)

Table 102
Factor eigenvalues, percentage of variance explained by each factor and the cumulative variance for the rotated factor matrix (palliative therapy group).

Factor	Eigenvalue	Percentage of variance	Cumulative variance (%)
1	3.00	15.81	15.81
2	2.20	11.58	27.39
3	2.21	11.63	39.02
4	1.74	9.14	48.16
5	1.50	7.91	56.07
6	1.85	9.73	65.80
7	1.47	7.56	73.36

The factor analysis of this data set produced seven orthogonal factors accounting for 73.36 per cent of the variance of the data. The variables loading on factor one are the patient and carers' perceived social support from family and friends. This represents a factor of perceived social support for the family. Factor two loads most heavily on the number and severity of symptoms and therefore represents a factor called symptomatology. Factor three loads on the HAD anxiety and depression scores of the carer and the carers' PAIS total score. This represents carer distress and adjustment to illness. Factor four loads most significantly on the EPI (extraversion and neuroticism) scores of the patient and the carer. This represents family personality. Factor five is a "unique factor" loading on a single variable, performance status. Similarly, factor six is also a "unique factor" loading on the single variable concerned with the PAIS total score of the patient. The final factor, factor seven loads most heavily on the HAD anxiety and depression scores of the patient. This, therefore,

represent patient distress. The seven factors and the variance accounted for each are shown in table 103.

Table 103
Factors derived from the rotated factor matrix and the variance explained: palliative therapy group.

Factor Name	Variance explained (%)
1. P.S.S. for the family	15.81
2. Symptomatology	11.58
3. Carer distress and adjustment to illness	11.63
4. Family personality	9.14
5. Performance status	7.91
6. Patients' adjustment to illness	9.73
7. Patient distress	7.56

(P.S.S. = perceived social support)

Factor analysis: conclusions

Factor analysis is a statistical technique developed by psychologists to reduce large amounts of data. The aim of this procedure is to identify structure within a set of observed variables without imposing any preconceived structure on the data. The technique can reduce the number of variables while maintaining as much of the original information as possible. This is particularly useful for understanding data and for testing the findings out in the future.

The variables from the three groups of patients and their carers in this study have been reduced using factor analytic techniques producing remarkably similar results. The same sets of data in the three groups produce optimum explanations of the variance of the data. In each case, in excess of 70 per

cent of the variance of each set of variables is explained. Interestingly, variables from the brief interview schedule such as attitudes to the illness and its treatment and demographic variables such as social class, marital status and sex do not enter the factor analysis. The factors instead support the results of the stepwise multiple regression analyses.

A number of common factors emerge in the three groups of patients and carers. Each group contains independent factors assessing distress of the patient, distress of the carer, symptomatology, perceived social support from family and/ or friends and specific personality characteristics in the patient and their carers. In the first line group, the factor "symptomatology" accounted for the largest amount of variance (13.35 per cent) followed by patient distress (11.35 per cent) and age (11.22 per cent). Carer distress (10.85 per cent) and perceived social support (10.66 per cent) were placed immediately after these three in terms of the variance they explained.

The follow up group indicates a different pattern of factors. Whereas symptomatology accounted for the most variance in the first line group, in the follow up group support from the family accounts for the most variance (12.15 per cent). This is then followed by patient distress (11.70 per cent), symptomatology (11.18 per cent), carer distress and adaptation to illness (10.83 per cent) and age (10.76 per cent).

If the first line management of lung cancer is considered, particularly the administration of very toxic chemotherapeutic agents, it is not surprising that symptomatology assumes its position in the factor analysis. In the follow up group, the patient is no longer receiving primary treatment for the disease and therefore the role of symptomatology decreases slightly, to be replaced by social support from the family.

In the palliative therapy group a general factor of perceived social support explains the optimum amount of variance (15.81 per cent) followed by carer distress and adjustment to illness (11.63 per cent) and symptomatology (11.58 per cent). It is interesting to note that in this group of patients they experience a similar degree of perceived symptomatology to the first line management group (see Table 30) but this factor maintains two different positions in the two analyses. In the palliative therapy group it is social support that explains most of the variance followed by carer distress, whereas in the first line group and the follow up group patient distress has been a more significant factor.

The three factor analyses also reveal some interesting findings regarding the interrelationships of some of the other variables. In two of the three analyses, performance status and extraversion of the carer and/ or patient load on the same factors (first line group and follow up group). Performance status is assessed by the physician and is concerned with the functional state of the patient, in terms of how much the person can do for themselves. This scale has, for many years,

been the most widely used tool in cancer care, "its status as a measure of quality of life rests upon its longevity and its widespread usage, rather than on any demonstrable methodological soundness" [Kind, 1988, p18]. The fact that it loads on the same factor as extraversion suggests that the physician may be reacting to this aspect of the patients' or the carers' personality rather than any objective measure of the distress. It is noteworthy that performance status does not load on the same factor (in any of the analyses) as symptomatology, reported by the patient, or the PAIS which may be a more direct measure of the disease impact. The physician may be making a judgement about the effect of the illness on the personality variables i.e. a person who is normally extraverted may appear to be less so and therefore they may assigned a poorer performance status.

Another relevant finding from the factor analysis is that carer distress and the PAIS total score of the carer load on the same factor in two out of the three factor analyses (follow up group and palliative therapy). This suggests that distress in the carer and the impact of the illness on their lifestyle are very closely linked, rather than consisting of separate independent entities. This is not necessarily the case for patient distress, however, which loads with the PAIS in the follow up group only and loads with personality variables in the first line group and stands alone as a unique factor in the palliative therapy group.

These three factor analyses considerably reduce the number of variables from the original data set suggesting that there is

considerable redundancy present. In addition, some interesting interrelationships between variables have been described as well as the changing importance of certain factors throughout the course of the illness and its treatment.

The factor analyses used with these data should be viewed with some caution. There are a large number of variables and a relatively small N which may distort the results. The factor analyses have been included as they support the results derived from the multiple stepwise regression analyses described earlier. The caution in interpreting the analyses should extend to the data from the three stages of lung cancer and its treatment as the small N extends to each data set compared with the large number of variables. Despite these limitations in the factor analysis however, the results are consistent with the regression analyses described earlier.

Summary of the results

1. Three groups of forty patients undergoing treatment for lung cancer and their primary carers have been assessed using a variety of measures.

2. Patients were either undergoing first line chemotherapy, were on follow up surveillance following chemotherapy, or were receiving palliative radiotherapy following chemotherapy and a period of surveillance.

3. The ages of the patients in the three groups were similar.

4. There was a more even distribution of males and females in the follow up group of patients and carers than in the other two groups.

5. Demographic data for the three groups of patients showed very similar distribution (marital status, social class, diagnosis, original treatment regimen).

6. There was no statistically significant age difference between the three groups of carers.

7. Demographic data for the three groups of carers showed similar distributions.

8. The majority of carers were spouses or other close relatives.

9. There were no statistically significant differences in mean HAD anxiety and depression scores between the three groups of patients.

10. A significant number of patients scored above the cut off level for anxiety on the HAD (possible "case") in the three groups of patients with the largest number in the palliative therapy group (47.5 per cent versus 42.5 per cent in the other two groups).

11. A significant number of patients scored above the cut off level for depression (possible "case") on the HAD in the three groups of patients (20 per cent in the first line group, 35 per cent in the follow up group and 17.5 per cent in the palliative group).

12. There were no statistically significant differences in mean HAD anxiety scores between the three groups of carers.

13. The majority of carers scored above the cut off score (possible "case") for anxiety on the HAD (65-75 per cent).

14. There were no statistically significant differences between the HAD depression scores of the three groups of carers.

15. A significant number of carers scored above the cut off level for depression (possible "case") on the HAD in the three groups of carers (32.5 per cent to 45 per cent).

16. A significant number of carers scored in the "probable case" level on the General Health Questionnaire (GHQ) and its subscale.

17. The HAD anxiety scores of the carers is significantly higher than the patients in all three groups.

18 There are statistically significant relationships between the mean HAD anxiety scores of the patients and those of the carers in the first line and follow up group.

19. The mean HAD depression scores of the patients and their carers are not significantly different in any of the groups.

20. The mean HAD depression scores of the patients and carers are only correlated significantly in the first line treatment group.

21. There were no consistent significant effects of gender on mood scores in any of the groups of patients and carers (but female carers in the palliative therapy group displayed significantly higher anxiety scores than male carers).

22. No significant effect of demographic variables on mood was observed in any of the groups of patients and carers.

23. The effects of self reported symptomatology on HAD anxiety in the patient only achieved significance in the

palliative therapy group. No effect of symptomatology on the HAD depression scores of the patient was observed.

24. The lung cancer cell type was not observed to have a consistent significant effect on mood state of the patient or carer

25. Lung cancer cell type was found to have a significant effect on carers' HAD anxiety and depression scores in only the follow up group.

26. Symptomatology reported by the patient was not found to be significantly associated with HAD anxiety or depression scores in the carer.

27. There are statistically significant differences between self reported symptoms of the patients in the three groups. This effect is also observed for performance status.

28. There were no statistically significant differences between male and female patients in the variables related to symptomatology.

29. There were statistically differences between the three groups of patients on the extraversion and neuroticism scores of the EPI.

30. There was a statistically significant difference between the three groups of carers on the extraversion score of the EPI but not on the neuroticism score.

31. There were no statistically significant associations between the extraversion and neuroticism scores of patients and their carers and HAD anxiety and depression scores.

32. There was no effect of gender on the extraversion and neuroticism scores of the EPI in the patients.

33. Female carers in the first line management group had higher extraversion (EPI) scores than male carers in the same group. This effect was reversed in the palliative therapy group with males having higher extraversion scores than female. No difference was observed in the follow up group.

34. There was no effect of gender on neuroticism scores in the three groups of carers.

35. Perceived social support from family and friends was not found to differ between the three groups of patients and their carers.

36. Highly significant associations were found between the social support scores of the patient and the social support scores of the carer.

37. No significant associations between social support from friends and family and anxiety and depression in the patient were found across the three groups.

38. At certain stages of the illness, significant associations were observed between social support from family and friends and anxiety and depression.

39. Dividing the results into high versus low social support continues to support the view that at certain stages of the illness high levels of social support are associated with higher levels of anxiety and depression in carers.

40. This does not support the view that social support acts as a "buffer" to stressful events.

41. Questionnaire data from carers regarding recent changes in social support do not support the view that the social support is a reaction to distress.

42. In the patients receiving first line chemotherapy, only those patients with greater symptomatology tended to have higher levels of social support from family and friends.

43. There was no statistically significant effect of patients' symptomatology on social support for the carer.

44. No association between age and social support in the patient was observed in any of the three groups.

45. Older carers had less social support from family and friends in the follow up surveillance groups and the palliative therapy group.

46. There was no effect of gender on social support in either patients or their carers.

47. No effect of attitudes to the illness and its treatment were observed in patients and their carers at any stage of the illness.

48. Lung cancer and its treatment was found to have a significant impact on all domains of the Psychosocial Adjustment to Illness Scale (PAIS) in the three groups of patients.

49. Lung cancer and its treatment was found to have a significant impact on all domains of the PAIS in the three groups of carers.

50. In a number of different PAIS domains the effect of the illness and its treatment is greater on carers than on patients. Patients in the first line group and palliative group, however, report a greater effect on their sexual relationship than the carer.

51. Symptomatology and certain PAIS domains were found to be correlated significantly in the palliative therapy group of patients only.

52. Correlations between symptomatology and PAIS domains of the carers did not achieve statistical significance in any of the groups.

53. There was no effect of gender in any of the PAIS domains of patients and their carers in any of the three groups.

54. Patients and their carers report significant fears and worries concerning the impact of the illness and its treatment and its effect on their lives.

55. The majority of patients and their carers hope for long term control of the disease at all stages of the illness.

56. The majority of patients and their carers understand the aims of treatment except in the palliative therapy group.

57. Patients and carers with an over-optimistic view of treatment do not experience any effect of this view on their anxiety and depression scores.

58. Patients and carers give a significant amount of time to thinking about the illness which changes over time.

59. Most patients and carers talk to others about their illness.

60. Patients perceive their spouse as giving them the most help during the illness and its treatment.

61. Carers perceive a variety of significant others as having helped them with the difficulties of the illness and its treatment.

62. Most patients and carers identify a source of help and support should they need it.

63. Most patients and carers have shared their fears and worries with each other during the illness.

64. Most patients and carers report that their relationship has become closer since the illness was diagnosed.

65. Most patients and carers report an increase in communication since diagnosis.

66. Patients and carers report that the main effects of the illness on the family are to cause distress or to create a greater appreciation of people.

67. Patients and carers report significant changes in their social interactions with friends and relatives outside their homes depending on the stage of the illness.

68. Patients and carers report significant changes in their leisure activities resulting from the illness.

69. Most carers perceive that they have a significant role to play in helping the patient fight the disease or come to terms with it.

70. The psychological state of the patient or the carer is contributed to significantly by the psychological state of the significant other.

71. Symptomatology, perceived social support, personality characteristics and age also may contribute significantly to psychological distress of the patient or their carer.

72. The General Health Questionnaire (GHQ) score of the carer is contributed to significantly by the depression and/ or anxiety score of the patient.

73. The GHQ score of the carer is contributed to significantly by their PAIS score.

74. The data in all three groups of patients and their carers can be successfully reduced using factor analysis.

75. The factor analysis can reduce the data to seven or eight factors accounting for between 73-82 per cent of the variance of each data set.

76. The factor analysis suggests some interesting interrelationships between some of the variables.

77. The data from the study raises some interesting questions for future cross validation research.

The hypotheses: accepted or rejected?

The hypotheses described in the methods chapter are now discussed briefly below in the light of the results of the study.

Hypothesis 1. There will be no significant difference in levels of anxiety and depression in patients at different stages of the illness and its treatment.

As there were no statistically significant differences in mean HAD anxiety and depression scores between the three groups of patients, it is therefore confirmed.

Hypothesis 2. Those patients with greater levels of physical symptomatology will experience greater levels of anxiety and depression.

This hypothesis was supported in the palliative therapy group of patients only, where anxiety was found to correlate with physical symptoms. In the other two groups of patients the hypothesis was rejected as no significant association was found between anxiety and depression and physical symptoms.

Hypothesis 3. Those patients with high levels of perceived emotional social support will have lower levels of anxiety and depression.

This hypothesis was not supported in any of the three groups of patients and was therefore rejected.

Hypothesis 4. The treatment of lung cancer will adversely affect other areas of patients' lives.

This hypothesis was confirmed in the three groups of patients.

Hypothesis 5. There will be no difference between the levels of anxiety and depression in patients and the levels of anxiety and depression in their primary carers.

This hypothesis was rejected as primary carers were found to have significantly higher levels of anxiety in the three groups than patients and a trend towards higher levels of depression.

Hypothesis 6. Statistically significant correlations will be found between anxiety and depression levels in patients and their primary carers.

This hypothesis was confirmed in the first line and follow up groups of patients and primary carers but rejected in the palliative group, with respect to anxiety only. In terms of depression, it was confirmed in the first line group but rejected in the other two groups.

Hypothesis 7. Statistically significant correlations will be found between physical symptomatology in patients and anxiety and depression in their primary carers.

This hypothesis was rejected in all three groups of primary carers.

Hypothesis 8. Primary carers with high levels of perceived emotional social support will have low levels of anxiety and depression.

This hypothesis was rejected in all three groups of primary carers.

Hypothesis 9. The treatment of lung cancer will adversely affect other areas of primary carers' lives.

This hypothesis was confirmed in all three groups of primary carers.

Hypothesis 10. The lives of patients and their primary carers will be equally affected by lung cancer and its treatment.

This hypothesis was rejected in all three groups of patients and primary carers.

Hypothesis 11. Anxiety and depression in both patients and their primary carers will be explained by an interaction of low social support, high physical symptomatology and anxiety and depression in the 'significant other'.

This hypothesis was rejected in all three groups of patients and their primary carers as the interaction tended to consist of high social support, high physical symptomatology and anxiety and depression in the significant other.

Chapter Nine

DISCUSSION AND CONCLUSIONS

Lung cancer is a major cause of death in industrialised countries the incidence has been steadily increasing since the early 1940's [Garfinkel and Silverberg, 1991]. Despite the numbers of people who are affected by this disease there have been few systematic studies of it's' psychological and social impact on patients and their families. In contrast, research in breast cancer has examined areas such as quality of life, supportive care, coping strategies and coping styles as well as a wide range of psychosocial issues [Fallowfield and Clark, 1991]. There are several possible explanations for the limited amount of psychosocial research with lung cancer patients. Metastatic disease is common at the time of diagnosis and the limited survival time, therefore, diminishes the opportunity for psychosocial investigations. Similarly, psychosocial interventions for patients with cancer are more likely to be applied to those with longer survival times. In addition, it has been noted that poor performance status and rapid disease progression in many lung cancer patients precludes studies that require patients' attentiveness and cognitive effort [Bernhard and Ganz, 1991]. Bernhard and Ganz also put forward the view that until recently, lung cancer has primarily affected men, and male patients may be more reluctant to participate in psychosocial research in which their emotional concerns are discussed.

The present study has attempted to redress this balance by conducting a study into the effects of lung cancer and its treatment on the patient and their primary carer at different times during the course of the disease. The illness has a rapidly fatal course and forces the patient and their family to confront many fundamental changes in everyday life. The treatment regimens are highly toxic and can produce their own psychosocial sequelae for all concerned. Family members play an important role in the physical and emotional care of the patient, yet little is currently known about the impact of the disease on their psychological and social function. The current study has been prompted by these concerns, and has viewed the patient and their primary carer both as individuals, and also as a "unit" in furthering the understanding of the impact of the illness and its treatment on a number of different areas of their lives.

Initial difficulties

The initial study design for this project was amended following early pilot work (see "Methods" chapter). In this preliminary study, patients and their primary carers would have been identified at the diagnosis of their illness and then assessed at monthly and subsequently three monthly intervals. This would have given a clear picture of the changing needs of the subjects as well the changing effects of the illness and its treatment. The model for this design had been a study conducted earlier in the same department where patients with lung cancer had been interviewed monthly from

the diagnosis of their illness. This study had worked successfully with good compliance from the patients themselves in the interviews in the completion and return of the questionnaires.

In the study described here, however, the carers had found the continual interviewing too onerous and stressful and, therefore, had not been able to comply. This in itself is an indication of the stressful nature of the illness and treatment. This early study led to a radical change in design in which patients and carers were identified at predetermined stages of the illness process. This design proved to be highly successful in terms of data collection and compliance.

The study cannot give a dynamic picture which regular assessment would have facilitated but the experience of the illness can still be described. The subjects have all experienced a very similar approach to treatment, whereby all the patients have received first line chemotherapy, or first line chemotherapy and follow-up surveillance, or first line chemotherapy, follow-up surveillance and palliative therapy. The effects, therefore, of each of these treatment stages on the patients and their carers can be assessed and compared and a description of the illness as a "process" constructed. In addition, the study required a single assessment when patients were either in the ward or attending out-patient clinics. Compliance was, as a result, greatly enhanced. The current study could more accurately be described as a "stage" model and not a "process" model as a longitudinal design was not able to be used.

Three groups of subjects

The three groups of patients and their carers are very well matched on a range of demographic variables (social class, marital status, diagnosis, original treatment regimen and relationship to the patient). There is a difference in the mean ages of the three groups of patients: the palliative therapy group are older than the follow-up group. This age difference is not apparent in the three groups of carers. In the analyses, however, there are no significant effects of age on the psychological and psychosocial variables and this difference does not significantly effect the interpretation of the results.

A potentially more vexing difference between the three groups of patients is the sex distribution, which is quite different in the follow-up group to the other two. There is no consistent effect of gender and this unequal distribution does not confound the results of this study. The three groups of patients and their carers can be viewed as three similar groups having had similar experiences of treatment.

Mood: Patient

The three groups of patients were not significantly different in terms of their mean HAD anxiety and depression scores. A trend was found for higher mean anxiety and depression scores in the follow up surveillance group although, this did not achieve statistical significance. Studies using other groups of cancer patients have reported a different pattern of

distress. Hughes [1985b], for example, reported a decrease in the prevalence of depression in a group of lung cancer patients over a three month period. This study assessed patients at diagnosis and later following treatment. Initially 26 per cent of patients were depressed but this had fallen to 16 per cent three months later. Silberfarb et al. [1980] reported higher levels of anxiety and depression at the time of recurrence of breast cancer than at other stages of the illness process. Cassileth et al. [1985], in a heterogeneous group of cancer patients, found that those receiving palliative therapy displayed "the highest anxiety levels, the most severe disturbance in mood and the poorest overall mental health" (p74).

A longitudinal study by Ell et al. [1988; 1989a; 1989b] conducted over a two year period found a pattern of increasing distress over time.

The literature, therefore, supports a view of steadily declining psychological functioning over the course of the illness. The current study describes a more complex picture of distress which it appears is exacerbated by the uncertainty of completing first line chemotherapy.

The view of increased psychological distress following the cessation of treatment is supported by other research [Futterman and Hoffman, 1973; Stone 1975; Wheatley et al., 1974; Koocher and Malley, 1981]. This period of "watching and waiting" has been termed the "Damocles Syndrome" by

the latter authors and is characterised by a time of great uncertainty, fear and apprehension. This is exacerbated by frequent investigations (X-rays, blood tests etc). It has been likened to an "emotional roller coaster" with levels of distress which continually rise and fall. This is further supported by findings from a study by Schag and Heinrich [1989], who interviewed 320 patients with cancer, a significant proportion of whom did not have active disease and were returning for out-patient follow-up consultation. Fifty six per cent of the sample reported that they were nervous on visiting the hospital and of these 30 per cent reported significant anxiety. Forty per cent reported anxiety when waiting to see the doctor and 56 per cent reported anxiety when waiting to find out the results of tests. These authors report that improved communication skills on the part of both the patient and the physician can help reduce some of the patients' anxiety. The most significant factor here, they suggest, is the uncertainty of the patients disease status.

In addition, many "survivors" of cancer have been found to fear recurrence of their disease and death [Northouse 1981,; Maher 1982; Cella and Tross, 1986]. Commenting on the importance and prominence of this fear, Northouse [1981] considered the role of communication. She noted that insufficient knowledge of when and if symptoms will recur reduces the individuals' overall sense of mastery and control of their life. In a study of 60 male survivors of Hodgkin's disease and 20 age-matched controls, Cella and Tross [1986] found greater death related anxiety in "survivors" in the first

two years after therapy when compared with those coping with a more protracted survival. Maher [1982] has also reported the presence of this existential anxiety during the active treatment phase of certain types of cancer and found that it persists for several months after the completion of therapy. This ranges from generalised anxiety to worry and anger and even thoughts of suicide. These findings suggest a general lessening of anxiety over time but lends support to the results of the current study in which the anxiety level remains elevated during the "no treatment, follow up period".

Such a pattern may be related to the specific type of cancer and its treatment. Tross et al. [1987] studied cancer specific and general psychological distress in survivors of testicular cancer (who had an excellent prognosis) and acute leukemia (poor prognosis). The results showed that the leukemia group had greater cancer specific distress and higher anxiety, chiefly related to persistent fears of recurrence. The leukemia group have certain similarities to patients with lung cancer in that the disease may not be detectable but in the future is likely to recur [Tross et al., 1987]. These effects may persist for many years in cancer patients. Fobair and Mages [1981], for example, found significantly lower levels of anxiety in long term survivors of cancer six years following diagnosis compared with those patients who had completed treatment in the previous year. The disease type and time since diagnosis are therefore important variables to consider in any longitudinal study of the psychological impact of cancer.

Many patients anticipating and attaining the completion of therapy do so with ambivalence and heightened anxiety [Maher, 1982]. Elation that the treatment is over is coupled with the anxiety of losing close contact with the treatment team. Maher speculates that this can be viewed as a "separation anxiety" and a fear of potential loss of medical control over the disease. In addition, Fobair et al. [1986] have found that any persisting disability or impairment of physical function following treatment serves to increase anxiety in the follow up period. These results are consistent with the data collected in the current study following the first line management phase when the patients move into a very uncertain period of repeated out patient clinic visits and routine monitoring, and a degree of persisting symptomatology.

The data from the current study also examines patients who score above the "case" level on the HAD (11-21). The number who score above this point for anxiety are statistically similar in each group, but a trend towards an increased number in the group undergoing follow up surveillance is found. It is also noteworthy that only one patient in the palliative therapy group falls in the "case level" of depression. This could be due to the alleviation of the distressing effects of physical symptoms for the patient by radiotherapy. This group have a poorer performance status than the other groups and an increased severity of symptoms. The fact that treatment is being administered to reduce the symptomatology may give the patients some hope.

An alternative "cut off" score to select on the HAD is 8+. When the distribution of patients is examined using this division, a slightly different pattern emerges. The number scoring above this level on the anxiety subscale demonstrates a trend towards increased anxiety during palliative therapy and it is noteable that the follow up group do not show a significant reduction: in the first line group 42.5 per cent score in the "case level" range; the follow up group 42.5 per cent and the palliative therapy group 47.5 per cent. The distribution of the depression subscale shows a different pattern. Twenty per cent in the first line group score above this level, 35 per cent in the follow up group and 17.5 per cent in the palliative therapy group. Again this demonstrates the psychological impact of the follow up surveillance period as well as that of palliative therapy. Other studies have reported that between 25-30 per cent of patients experience a significant degree of anxiety and/ or depression [Plumb and Holland, 1977; Maguire et al., 1978; Holland, 1981; Bukberg et al., 1984; Devlen et al., 1987b] and a raised levels of distress in patients undergoing palliative therapy have been noted [Hinton, 1963; Cassileth et al., 1985]. Increased anxiety in those patients undergoing palliative therapy may not be surprising. They often experience many distressing symptoms such as pain, breathlessness, dysphagia or weight loss and may be functionally limited. The results of the current study, for example, demonstrate an association between symptoms reported by the patient and anxiety in this group. In addition the aim of treatment is not to prolong life but to alleviate

these symptoms, in fact, this period has been regarded as representing "nearness to death" [Cassileth et al., 1985].

Direct comparison with other studies is complicated as they often utilise heterogeneous groups of patients, different assessment tools and do not specify the stage of the illness that the patient has reached. The current study assessed patients and carers at carefully defined times during the illness process with a common treatment approach. Other studies such as those by Ell et al. [1988; 1989a; 1989b] and Goldberg et al. [1984] have selected assessments based on convenient time points (one year, two years or three months) rather than on the timetable dictated by treatment regimens. This necessarily complicates comparison of results. In the studies by Ell et al. enormous variation could occur between time points which is not detected. A further factor is the range of treatment approaches that patients were subjected to in the studies by Ell et al. as the patient groups were selected from 23 hospitals in Southern California with no "single treatment setting" defined.

Mood: Primary Carer

One of the principal findings of this study has been the effect of lung cancer and its treatment on the mood state of the carer. There have been very few studies examining both the patients and the carers in the world literature despite the obvious importance of the latter in the patient's life and concerns. The studies that have been undertaken in this field

have produced equivocal findings and have suffered from a number of serious methodological shortcomings.

In the present study carers demonstrated consistently high mean anxiety scores at the three stages of the illness. In fact, the mean scores for the three groups placed them above the cut off scores of the HAD scale and into the clinically significant range. There was, however, no statistically significant difference between the mean scores of the three groups.

When the data is examined in terms of cut off scores, high levels of distress are revealed. In the first line chemotherapy group 75 per cent score above the "normal" range, in the follow up group 70 per cent, and in the palliative therapy group 65 per cent. These percentages are much greater than those found in the groups of patients. The data for the depression subscale is less dramatic but still represents a significant degree of mood disturbance. In the first line group 45 per cent scored above the "normal" range, in the follow up group 25 per cent, and in the palliative therapy group 32.5 per cent. This represents an enormous burden of distress amongst the carers of patients with lung cancer. Currently, there are no studies suitable in design with which these figures can be compared.

The data from the present study suggests that throughout the course of the disease and its treatment carers experience high, unremitting levels of anxiety. This is the first time that such a

finding has been produced and has important implications for planning interventions which will be discussed further later.

The pattern of mean HAD depression scores for the carer is different from that of anxiety. There is no statistically significant difference between the three groups, but the trend is towards a lower mean score in the follow up group of carers. The decrease in mean depression score could be due to the fact that the patient is not undergoing treatment and therefore, may be relatively well when compared with the period when they were receiving chemotherapy. They may be more active and able to live a more "normal" life. This may mediate depression but worrying thoughts regarding the illness and the future may persist, which would explain the persistent anxiety. Not surprisingly, the mean depression score then rises in the palliative therapy group although not to the level found in carers in the first line management group.

The mean depression scores for carers is less than that of anxiety, yet a significant number in each group still score above the "cut off" level and it still remains a significant problem over the course of the illness process.

Mood: The Relationship between Patients and their Primary Carers.

When the mean anxiety scores of the patients and their carers are compared, at each stage of the illness there is a highly significant difference between them, the carer having a higher mean score on each occasion. This is contrary to the findings of

a number of studies. Cassileth et al. [1985] investigating cancer patients and their next of kin, reported that "as a group, patients displayed greater mood disturbance...than did relatives" (p 74). Goldberg et al. [1985] in a study of lung cancer patients and their spouses, found that over a six month period following diagnosis, the psychological distress in the spouses reduced significantly. These findings are not supported in the current study. A reduction in the mean anxiety score of the carer is seen but this fails to achieve statistical significance.

The relationship between the psychological state of the patient and that of the carer is clearly complex. Despite the fact that there are significant differences between their anxiety and depression scores in the current study, there are also significant associations.

The anxiety scores of the patient and carer are significantly correlated in the first line management group and in the follow up groups, whereas the correlations between their depression scores fails to achieve statistical significance. Despite the correlation in anxiety scores only 20 per cent of the variance in the first line group and 14 per cent of the variance in the follow up group is explained by them.

This relationship has been explored further using a series of multiple stepwise regression analyses. This suggests that in the three stages of the illness studied, the psychological state

of the carer contributes significantly to anxiety and/ or depression in the patient. In the same way the psychological state of the patient contributes significantly to the anxiety and/ or depression in the carer, but this effect is only found in the first line management and follow up surveillance groups. In the palliative therapy group the contribution of the psychological state of the patient is displaced in the regression analysis by other factors which include the patients' total PAIS score (which is indicative of a more global impact of the illness on the patients' life affecting the carers' mood). In addition, The aim of palliative therapy is to relieve symptoms rather than to prolong life and it has been suggested that this stage is associated with "nearness to death" [Cassileth et al., 1985]. This fact may be a significant contributory factor to carer distress at this time. The majority of them (65 per cent), for example, accurately report that the aim of treatment was to relieve symptoms rather than to prolong life.

The data suggests that the interaction of the psychological state of the patient and their carer may be mediated by a range of other factors in addition to the stage of the illness and its treatment.

Studies examining the relationship between the psychological state of the patient and the psychological state of the carer or spouse have produced equivocal results. Cassileth et al. [1985] found that the psychological status of patients and relatives was significantly correlated across various cancer types (including lung cancer). Cassileth et al. conclude that, "It may

be inferred that relatives do provide a psychosocial environment to which the patient reacts and, conversely, that patients similarly influence the level of distress or adaptability exhibited by their relatives"(p76).

These results are supported by Keitel et al. [1990] in a group of patients with mixed cancer types undergoing surgery. The results demonstrated that the "pattern of distress was strikingly similar in patients and spouses" (p150). In addition, this study also found that spouses reported greater distress than did patients both pre and post-surgery, but both had lowered their distress at the post surgical assessment. Unfortunately, this study only deals with surgery and does not continue the assessment thereafter. Oberst and Scott [1988] reported similar results in a group of cancer patients undergoing surgery, again with a very short follow up period.

Similarly, Northouse and Swain [1987], using a short follow up period (three days following surgery for breast cancer and one month later), found significant correlations between the mood scores of patients and their spouses. The mood disturbance reported by the husbands was similar to that reported by the wives who underwent surgery. These researchers also found that there was no significant improvement over time in the distress levels for either wives or their husbands.

Coursey et al. [1975], on the other hand, found that family members scored higher on measures of state anxiety than did the patients but that there was no significant correlation

between the two. Goldberg et al. [1984] also found little relationship between the psychological state of the patient and their spouse, but rather that the psychological state of each were mediated by quite different factors independently of the other. For the patient, mood disturbance was correlated with physical symptoms and for the spouse distress was correlated with low levels of social interest and involvement and not the patients' symptomatology.

Comparison of studies in this area is extremely difficult and each must be assessed on its own merits. The range of study designs is extremely diverse using different groups of patients undergoing different treatments assessed by different assessment schedules. Even studies with lung cancer patients are difficult to compare due to their varying designs. Goldberg ,for example, assessed lung cancer patients having a range of treatments every two months for six months. Each cancer type and treatment approach may impose its own stresses upon the sufferers and their families and thus mediate the relationship between the interaction of their respective mood states.

Mood: the contribution of other factors.

One of the major factors associated with psychological distress in cancer patients, according to the literature, is symptomatology related to the disease and its treatment. In the current study no significant associations were found between the number of symptoms and side effects of treatment, the severity of these symptoms and side effects, performance status and time since diagnosis in the first line

management and follow up surveillance groups. In the palliative therapy group, however, there was a statistically significant association between the number of symptoms and side effects and anxiety, but not depression. The predominant symptoms experienced by this group of patients were pain and breathlessness. Both of these symptoms are recognised as having a marked effect on the psychological state of the patient [Burns and Howell, 1969; Foley, 1985; Sandhu, 1986; Jay et al., 1986; Breitbart, 1989]. The physical symptoms alone, therefore, do not produce a consistent association with distress in the patient groups.

Symptomatology present in the patient had no effect on the mood state of the carer. None of the illness variables when correlated with the carers' anxiety and depression achieved statistical significance. This finding remained consistent across the three groups of carers.

These results, to some extent, are consistent with other findings reported in the literature, although the caveats previously described must not be ignored. Goldberg et al. [1984] found that six months after diagnosis, depression in lung cancer patients was highly correlated with the Karnofsky Performance Status, yet no significant correlations were observed at two months and four months after diagnosis. In the same study no significant correlations were observed between the Karnofsky Performance Status of the patient and the depression score of the spouse. From this paper, however,

no details regarding type of treatment or the stage of disease are given.

Hughes [1985a] found that there was a highly significant association between Karnofsky Performance Status and depression, and between the presence of hypercalcaemia at the time of diagnosis but before the start of treatment. This assessment would have been conducted approximately 4-6 weeks before the assessment of the first line management group in the current study. At six month follow up there was still a significant association between depression and degree of physical disability. A significant number of these patients (30 per cent) were still receiving combination chemotherapy for their disease, again, complicating comparison.

Numerous studies examining the early period (up to six months after diagnosis) have reported a significant association between physical symptoms and psychological distress in patients [McCorkle and Quint-Benoliel, 1983; Hughes, 1985a; Bukberg et al., 1984; Cella et al., 1987]. Some studies, however, have failed to describe such an association [Taylor et al., 1985; Cassileth et al., 1984]. The discrepancies may be related to the different types of cancer studied, the different assessment tools used and the different treatment approaches employed [Cassileth et al., 1984].

Beyond this early period, however, little published data exists regarding the relationship between physical symptoms and distress. Pettingale et al. [1988], failed to find an association

between symptomatology, extent of disease and distress at 12 months following diagnosis and treatment of breast cancer and Hodgkin's disease but did find some evidence of a trend towards an association in Non-Hodgkin's lymphoma. Espie et al. [1989] failed to find an association between symptoms and anxiety and depression several years after patients underwent surgery for the intra-oral cancers, whereas Hinton [1963] reports an association between pronounced symptoms and depression in patients with terminal illness.

The results from the published literature regarding the effect of symptoms on distress in the patient are far from clear. For the effect on the relative there is even less support. The current study finds no association at any stage of the disease between symptoms and mood state. This supports the study of Goldberg et al. [1984] who also examined a group of carers of patients with lung cancer but fails to support the research of Cassileth et al. [1985] who found that carers of patients receiving palliative therapy, and therefore had more symptoms, tended to be more distressed.

In the current study the type of lung cancer and the treatment regimen employed during the initial management do not have an effect on the mood state of the patients. This finding is contrary to a number of studies which report a differential effect of cytotoxic chemotherapy on mood [Silberfarb et al., 1983; Van Praag 1982; Adams et al.,1984; McDonald et al., 1987].

The effect of the type of lung cancer (cell type) on the carer was not evident in the first line management group or the palliative therapy group but was evident in the follow up group. At this stage of treatment the carers of those patients with non small cell lung cancer were significantly more anxious and depressed than those with small cell lung cancer. This is a difficult finding to interpret and may be due to a range of possible reasons such as chance, the interpretation of a specific side effect or symptom by the carer, or even subtle differences in the information given to those carers at some time during or following first line management.

Gender and age have no consistent effect on mood in either the patients or the carers. The only effect of note with respect to age and mood was that female carers in the palliative therapy group had significantly higher anxiety levels than male carers. This finding has been reported previously, and is viewed as a form of "anticipatory grief", [Holland, 1976; Goldberg et al., 1984]. Female carers during palliative therapy, it has been argued may be preparing for life alone, and for many this is extremely worrying as they may have always been dependent on their husbands [Goldberg et al., 1984]. Many middle aged women in the current study, for example, had never worked in their lives. The lack of a consistent effect of gender on mood in this study, however is supported by data from other studies in the field of lung cancer which have produced similar findings [Hughes, 1985a; Cassileth et al., 1985]. Previous studies with heterogeneous groups of cancer patients, have usually found that females are more distressed

than males and that younger aged patients are more distressed than older patients [Coursey et al., 1975; Goldberg et al. 1984; Plumb et al., 1977; 1981; Cassileth et al., 1984]. This suggests that the relationship between variables such as gender, age and mood, therefore, may be an effect which varies according to cancer type. This is clearly an area for further investigation.

Adjustment and Coping

Studies have often invoked a concept of "coping" to explain the adjustment of patients and/ or their families to cancer and its implications [Weisman and Worden, 1976-77; Lloyd et al., 1984; Ell et al., 1989; Keitel et al., 1990]. In these studies adjustment is often associated with a reduction in distress over time following diagnosis. In the current study no such reduction in distress is observed across the groups. In this study, as in numerous other studies described in the literature, the diagnosis of cancer is regarded as a crisis for all concerned and a number of theoretical models are available to explain the coping and adjustment reaction to this [McCorkle and Quint-Benoliel, 1983]. A commonly used model is that of Lazarus [1980] and Folkman and Lazarus [1980] in which the subject makes cognitive appraisals of the "threat" of the illness. At the diagnosis of cancer, the patient and carer would make an appraisal based on "life-threat" probably derived from fears of death, physical suffering, deterioration, recurrence and spread of the disease. The theory would predict that this would relate negatively to adjustment and would create a disruption to the subjects' equilibrium.

Following this initial period of crisis, secondary appraisal would take place where the subject evaluates their coping resources and the available options towards resolution of the crisis. The introduction of treatment options to the patient and their carer, coupled with information, may help the development of the perception of control over the situation. This perceived control has been explained in terms of providing a source of mastery over the situation [Taylor, 1983] which in turn leads to a state of reduced distress and increased coping [Taylor et al., 1984].

This theoretical perspective explains the findings of reduced distress over time. Obviously as the illness progresses and new crises occur a continual process of re-appraisal takes place leading to a reduction in levels of distress.

The results from the current study suggest that such a process may not be occurring effectively, or that the assessment points used do not detect it. The diagnosis of lung cancer for the patient and the carer may be imposing multiple stresses including pain, threat to life, hospitalisation, effect on employment, effect on family and special treatment procedures. In addition, the patient and carer must try to preserve emotional equilibrium as well as to maintain relationships with friends, family and hospital staff. A key feature for facilitating a coping response is the type and amount of information that is given at diagnosis. Obviously, the informational needs of patients and carers change throughout the illness "process" and new information may

need to be assimilated as the clinical picture changes. Mages and Mendelsohn [1979] found that the informational needs at diagnosis are concerned with the implications of the disease on the patients' life and the hopes and expectations of treatment.

Following this early period, patients tend to seek maximum information regarding prognosis [Feldman, 1978], effects on current and future lifestyle [Jones, 1981], and the effect on the family [Feldman, 1978].

In the current study the prevalent practice in the oncology department was to give patients the most accurate information possible about their illness. Patients were, therefore, told that their illness was incurable and that the aim of treatment was control of the disease for as long as possible. From the data collected in this study there is no objective assessment of the actual information given at diagnosis. In the first line group of patients and carers and the follow up group, however, the majority accurately report the aim of treatment suggesting that the information has been correctly assimilated. The majority of carers in the palliative therapy group also follow this pattern in accurately reporting the aim of treatment but this is not reflected in the patients' reports. A significant proportion of the latter (35 per cent) report that the aim of treatment is "cure". This suggests that for most patients and their carers, accurate information has been communicated, at least about the aims of treatment. Some people, however, could be regarded as using "denial" as a coping style particularly in the later stages of the disease.

Interestingly, the mean anxiety scores of these patients were not significantly different from those who accurately reported treatment intent. In addition, those carers who believed that the aim of treatment was curative at this stage (palliative) were not significantly more anxious or depressed than those who correctly reported the aims of treatment.

If a diagnosis of lung cancer carries with it a high level of uncertainty, then perhaps this uncertainty persists throughout the illness and maintains the level of distress in patients and their carers. Certainly the patients and their carers in the current study do not demonstrate obvious adjustment leading to a reduction in distress. A further explanation put forward by McCorkle and Quint-Benoliel [1983] concerns the effect of symptoms that are continually present. They speculate that even though patients may have completed treatment they may still be experiencing symptoms, either from the illness or treatment (as in the current study), these symptoms serve as a constant reminder of the illness and its implications and, therefore, mediate against any reduction in distress. This, in turn, may have an effect on the carer, who will be very aware of the symptoms and may have very clear recollections of information given at diagnosis (that the illness is incurable). These data have implications for the type and timing of information that may need to be imparted by health care professionals to patients and their carers during visits to the hospital. It also suggests that patterns of adjustment may vary depending on the type of cancer from which the patient is suffering and treatment approach that is being used.

Social Support

The data described in this study show that there is no statistically significant difference between the three groups of patients and carers with respect to perceived social support from family and friends. The data also indicate that the perceived social support from family members and friends between patient and carer are, not surprisingly, correlated.

In the present study social support does not follow a pattern of reduction over time which has been reported by other researchers. In such studies typical expectations about independent functioning, for example, have been found to colour supporters' reactions to the victims of crisis and thus limit the support given, there is an expectation that distress is "time limited". Vachon [1979] reported that women with breast cancer are expected to resume quickly their normal functioning once medical intervention has been completed, despite the fact that many women are distressed long after successful surgery. Walker et al. [1977] found that widows frequently report that close family members expect them to limit their grieving following the loss, and reduce their supportive behaviours accordingly.

Perceived social support and anxiety and depression in the patient were not found to be significantly correlated at any

stage of the illness process. The association between social support and mood in the carer is more complex.. There is a highly significant (positive) correlation between anxiety and social support from the family in the first line management group only. The correlation between social support and anxiety at other stages of the illness process fails to achieve statistical significance. The correlations between depression and social support from family achieved significance in the first line management group and the follow up group but not in the palliative therapy group and the correlations between social support from friends and depression achieve significance only in the follow up surveillance group.

These significant associations indicate that high levels of distress in these groups are associated with high levels of social support. The measure of social support employed in this study was the Perceived Social Support Scale developed by Procidano and Heller [1983]. The scale, unlike many other scales available, uses a specific definition of social support, that of "perceived emotional social support". Numerous studies have found that high levels of emotional support are related to improved levels of distress [Brown et al., 1975; Vachon, 1984; Funch and Mettlin, 1982]. The Perceived Social Support Scale has been used to examine the stress buffering effects of other disorders and illnesses such as multiple sclerosis [McIvor et al., 1984], alcoholism [Clair, 1988], and breast cancer [Jones and Reznikoff, 1989]. These studies support the "buffering" hypothesis of social support in that high levels of perceived emotional social support are associated with lower levels of

distress (a significant inverse correlation). How then are we to explain the results of the current study which appear to contradict those from the literature?

One explanation of the results could be that the level of social support is a reaction to the distress exhibited by the individual involved. The significant associations between social support and anxiety and depression in the carer are found in the first line group and the follow up group. These periods are associated with the recent diagnosis of the illness and a time of great uncertainty. The perceptions of the carer in the first line group also support the supposition that support is a reaction to level of distress, as they feel that support has increased. The follow up group of carers, however, feel that there has been a decrease in support. In addition, when asked about perceived changes, specifically from family and friends in the past month, the majority of carers in each group felt that there had been no change. This pattern of response was also found in answer to questions concerning the availability of family and friends in whom they could confide. This suggests that the social support is not a reaction to distress or one would expect the carer to recognise an increase in the availability and amount of support.

Some caution must be exercised in arriving at this conclusion as the current study may not provide enough data to substantiate it. The responses are concerned with perceptions of change in support over a relatively recent time period, the last month. The distress exhibited by patients and their carers

may have persisted for a longer period of time. The increase in support, therefore, may have occurred some time ago in response to this and the respondent may not be including this in answer to the questions. Even in the first line management group, the levels of distress may have been rising for some time, for example, since the patients first developed their symptoms. Aitken-Swan and Paterson [1955] reported that many patients suspect their diagnosis when their symptoms first occur, before they visit their doctor. Other researchers have reported that levels of distress rise during this period of time [Green, 1976]. The social support in this first line group may, therefore, have been a reaction to this early rise in distress but there is no way of detecting whether the distress preceded the social support or *vice versa*.

Researchers have commented that not only the stressor but also the "victims'" distress can elicit support but this distinction can be very difficult to make [Shinn et al., 1984]. These authors have commented that both the recipient and the giver of support themselves, may not be aware of whether they are reacting to the fact of having cancer, or to the distress of its victims.

An alternative explanation of the data, therefore, could be that the social support from family and friends is a reaction to both the diagnosis of cancer and the distress in the carer. The significant correlations, after all, are seen in the first line management group and the follow up group of carers. The data from the present study are unable to answer the question

with certainty but some of the responses suggest that there have not been noticeable changes in social support for carers.

Another explanation that could be postulated to explain these results is that social support is indeed stressful in itself. Those carers with high levels of social support are more distressed as a result of it. Blau [1964] suggests that social interaction involves benefits and costs for both recipients and providers of support. Providers may obtain intrinsic satisfaction for providing support, but they expend time, energy, and resources in the process. Recipients can clearly benefit by receiving supportive resources but may also experience stress as a result of supportive interactions as the norms of reciprocity and equity suggest that they should repay the support received. This inability to reciprocate can create stress and distress in the receiver [Shumaker and Brownell, 1984]. Another explanation of the deleterious effects of social support is that it may threaten the recipients' self esteem. The social support may imply a superiority-inferiority relationship which conflicts with values of self reliance and independence, or may lead the recipient to admit to distress and therefore vulnerability or a perception of weakness [DiMatteo and Hays, 1981; Fisher et al.,1982; Chesler and Barbarin, 1984; Shumaker and Brownell,1984].

Croog [1970] reported that social support from the family can serve as a source of distress due to a conflict of role or value. The emotional support provided by the family may accentuate to the recipient the reversal of roles created by their illness

and its treatment which may in turn lead to distress. DiMatteo and Hays [1981] have reported this effect in a number of other serious illnesses (such as heart disease and multiple sclerosis). Hyman [1971] in a study of patients with a variety of chronic illnesses, found that those people whose families were more attentive to them or allowed them to express their fears and worries more often, tended to be more disabled and more distressed than those without this form of support.

One study in particular produced very similar results to the present study. Revenson et al. [1983] found that emotional support had very little effect on adjustment in patients with cancer. In patients not undergoing chemotherapy or radiation treatment, or with limited functioning, this type of support increased negative mood and decreased self-perceptions of worth or mastery. Revenson et al. suggest that at certain times supportive behaviours may represent threats to the recipients' autonomy and self worth. Social support may actually constitute a source of stress. The expression of a warm empathetic environment from family or friends may serve to highlight the recipients' inability to reciprocate that support. This may be complicated further in an illness such as lung cancer which has a poor prognosis, if the recipient (patient or carer) does not foresee a possibility of returning that support in the future.

The results of the present study could be interpreted in this light particularly in view of the respondents' perception that social support has been relatively stable in the recent past.

This would lead us to conclude, in a similar vein to Revenson et al., that, at certain times of the illness process, social support acts as "non support" and could be viewed as a source of distress in itself. This is consistent with a view shared by several other authors [Heller, 1979; Billings and Moos, 1981]. In fact, Heller [1979] suggests that social support may serve as both a source of, and a buffer against stress and, therefore, it may not be possible to identify consistently "positive" or consistently "negative" effects.

One could speculate that the emotional support in the current study is being provided by people who are distressed themselves by the patients' illness (family and friends). Certainly the impact of cancer may affect a wide range of individuals. This may mean that those people who are providing the support are too stressed or distressed to provide effective support to each other.

In a study of the effects of war, for example, on women whose "loved ones" were in the armed forces, Hobfall and London [1986] found that higher levels of perceived emotional support were related to more, not less psychological distress. The findings could be interpreted that social support leads to greater distress and is stressful in itself. Hobfall and London, however, found that there was a "pressure cooker effect", whereby those with greater social support were exposed more frequently to rumours and to constant confrontation with the reality of war through their interaction with others in similar circumstances. Other studies have suggested that individuals

exposed to a common crisis may compound their distress through interaction with each other [Myers and Lamm, 1976]. Marlowe [1979] found that soldiers exposed to a combat situation often develop psychological distress in groups. Marlowe discovered that rather than behaving as a supportive confidant to those who develop distress, the supporter, who is also vulnerable, may develop distress themselves and a circular reaction is formed.

A similar effect could be taking place with lung cancer patients and their carers. The emotional support being assessed here, is support provided by family and friends who may be distressed themselves. However, in this current study we have no way of identifying this. They may be still providing emotional support, but their distress, interacts in a negative fashion with the recipient of that support and it therefore fails to "buffer" the stressful effects of the illness and its treatment. This area is certainly worth further investigation to ascertain the validity of such a supposition.

The present study suggests that social support may be associated with other variables in addition to the stigma of cancer and the presence of psychological distress. In those patients receiving first line chemotherapy, for example, significant correlations are found between self reported symptoms and their severity and perceived social support from family and friends. This association, however, is not sustained at other stages of the illness, nor is the social support for the carers associated with the patients' symptoms

and their severity. This group of patients undergoing first line chemotherapy are prone to a number of influences. Their illness has been diagnosed relatively recently, their carers tend to be very distressed, they are undergoing chemotherapy, and as a result, may be experiencing a range of symptoms and side effects. It is, therefore, difficult to disentangle these complex effects precisely.

A number of studies have reported, however, that those patients who are more debilitated by their illness and/ or its' treatment, report lower levels of social support than those who have completed their treatment. Peters-Golden [1982] found that patients with breast cancer undergoing palliative chemotherapy were more likely to report inadequate levels of social support than those who had received curative treatment. More recently Willey et al. [1990], in a large study of 1,581 newly diagnosed patients with cancer reported that those patients who were more impaired, received less social support. These patients complained principally of pain and had a poorer prognosis. Closer examination of this data, however, reveals that the patients with lower levels of social support also reported more days spent in bed, which in turn led to lower levels of social activity. In reality, therefore, this latter study is actually measuring an individuals' ability to obtain social support rather than the direct effect of symptoms on social support.

The present study reports the opposite of this result. The correlation is a positive one: the more symptoms one has and

the more severe they are, the more likely the patient is to receive social support. The fact that this situation is only found in the first line management group of patients suggests that it is not merely the presence of symptoms that increases social support but other factors as well.

Social support in carers was found to be inversely related to age in the follow up and palliative therapy groups. The older carers received less social support from both family and friends in these groups. This finding is consistent with a number of studies reporting the same type of statistically significant inverse correlation [Zautra, 1983; Heller and Mansback 1985; Vaux 1985; Cutrona, 1986].

The social support in both patient and carer in the present study does not correlate with personality variables. This suggests that social support or the reporting of social support by the respondent cannot be explained by specific characteristics of the individual. Henderson et al. [1981], for example, found that characteristics such as neuroticism can negatively affect the evaluation of support availability in a spurious manner.

The failure of perceived emotional social support to "buffer" the distress associated with lung cancer in the present study may also be related to the nature of lung cancer itself. The beneficial effects of emotional social support have been reported in illnesses such as breast cancer [Bloom, 1982; Jones and Reznikoff, 1989), multiple sclerosis [McIvor et al., 1984],

alcoholism [Clair, 1988], and intestinal malignancies [Dunkel-Schetter, 1984]. These illnesses tend to have a longer duration than lung cancer. One could postulate that lung cancer, because of its demanding treatment regimens and its extremely poor prognosis, imposes a complex array of stressors on both patients and their carers.

Driever and McCorkle [1984] suggest that the diagnosis of lung cancer affects every aspect of life during the initial period, with continuing difficulty in adaptation over many weeks or months. Hughes [1985a] found that 16 per cent of patients, prior to having the diagnosis confirmed had symptoms of depression, suggesting a suspicion of the seriousness of their situation and perhaps an anticipation of the diagnosis.

Rowland [1989] supports the view that the diagnosis and treatment of lung cancer is composed of multiple complex stressors. She views this in relation to the developmental stage that the adult has reached in their life. As lung cancer tends to be an illness of "middle age", the issues it raises are related to survival, coping with treatment, attractiveness, sexuality, financial concerns, ability to work, ability to socialise and perhaps seeing ones' children establish their own independence in the world. In addition, there may be difficult issues relating to having to be "cared for" and "caring for" and a period of "invalidism".

These multiple stresses may be further complicated by the fact that there is a very strong association between lung cancer and cigarette smoking. This may lead patients to believe that they "brought the illness on themselves" or for those people who are not smokers, they may feel they have developed the illness as a result of inhaling others' smoke. This complicating factor may present a difficult and complex problem for patients and their family alike [Lebovitz et al., 1983; Cooper, 1984]. Some authors have viewed the reaction of patients to a diagnosis of cancer as a "grief" reaction which may persist through the treatment of the illness and beyond [Holland, 1976].

Revenson et al. [1983] describe this pattern of multiple stressors persisting well beyond the diagnosis. The treatment may lead to strained, disrupted interpersonal relationships as well as diminished social contact. Revenson and her colleagues questioned their sample of patients about the range of stresses that the disease imposed. Fifty per cent of respondents reported fears and anxieties related to death, 38 per cent reported stress related to disease and treatment symptoms (nausea, weakness, hair loss and fatigue), 31 per cent reported stresses related to limitation of mobility and activity, and 25 per cent reported stresses related to problems with social relationships. They also found a series of more minor stresses related to emotional reactions to being ill and complaints about the quality of health care received. In Revenson's study respondents tended to identify a number of these stresses rather than one.

The present study demonstrates that lung cancer and its treatment is associated with a wide range of psychosocial sequelae for patients and their families. Given the complex nature of the illness, it is unreasonable to expect social support to be able to reduce the distress that this may produce. Perhaps the stress buffering effects of emotional social support would be more apparent if the stressors were not so interwoven. Certainly, some aspects of the illness have been linked to greater distress than others. Meyerowitz et al. [1979], for example, have found that undergoing chemotherapy and being physically limited in one's ability to perform daily functions of living have been associated with greater emotional distress than some other aspects of the disease and its treatment (undergoing radiotherapy). However, Revenson's results demonstrate that social support alone is inadequate in reducing the distress associated with this complex array of stressors.

In the present study ample evidence is presented of the complex nature of the illness and its treatment. The stepwise multiple regression analyses that have been performed indicate that a range of variables contribute to the distress in both patients and their carers.

The psychological state of the "significant other" was consistently found to have a significant impact on the other person. In addition, other variables such as perceived social support, the number and severity of symptoms, psychological

adjustment to illness and certain demographic factors (age) and personality traits were also found to contribute significantly to distress in the patient or their carer. These combinations of variables support the complex nature of cancer and its treatment. Other studies have concentrated upon other constellations of variables contributing to distress in other types of cancer. Ell et al. [1989] found that social support and a sense of personal control over the disease were associated with a better psychological status. Goldberg et al. [1984] found that depression in patients with lung cancer was associated with a poor physical status whereas the spouses' depression was associated with low levels of social interest and involvement.

The present study indicates that aspects of the patients' environment adversely affect the carer and *vice versa*. Although such a statement may seem an obvious one to make, other studies in the literature fail to consider the reciprocal effects of patient and carer variables.

Further support for this multistressor view of lung cancer can be found in the factor analyses performed in the current study. At each stage of the illness and its treatment the large data sets can be reduced to either seven or eight independent factors. These factors support the findings of the multiple stepwise regression analyses performed on the data. In each of the three groups, distress in the carer and distress in the patient form independent factors as does social support and symptomatology. Other factors including age, adjustment to

illness and certain personality characteristics also can be found as independent factors.

Given the complex nature of the illness and its treatment it is not surprising that a single variable such as social support is unable to reduce significantly the distress associated with it. In fact the current study suggests that emotional support may actually contribute to anxiety and depression in both patients and their carers.

The distress associated with the illness and its treatment may require other types of social support to ameliorate it. Social support, after all, is a complex concept itself composed of a number of different types. These include:

1. The expression of positive affect which may include information that one is cared for, loved or esteemed;
2. Encouraging the open expression of beliefs and feelings;
3. Acknowledging the appropriateness of a person's beliefs or feelings;
4. Offering advice or information;
5. The provision of material aid;
6. The provision of information.

These different types of social support have been described by Wortman [1984] who makes the point that there is considerable overlap between them. In addition, other authors have argued that not all types of support are equally effective in reducing distress [Thoits, 1982].

The current study utilised a measure of perceived emotional support as this had been found to be the most helpful to patients in reducing distress and giving reassurance [Moos and Tsu, 1977; Jones and Reznikoff, 1989]. In addition, Dunkel-Schetter [1984] in a study of 79 patients with breast or colo-rectal malignancies found that emotional support was reported as being the most helpful. Eighty one per cent of respondents in her sample reported that the most valuable emotional support came from family and friends. In contrast to this, Dunkel-Schetter found that 44 per cent of respondents reported that provision of information and advice by family and friends was unhelpful. This result was replicated more recently by Dakof and Taylor [1990] in a group of 55 patients with mixed cancer types.

Lung cancer may present a different or more complex range of difficulties for patients and their carers, which may require more than just emotional social support. This is consistent with the view of researchers who maintain that each component of social support should be considered as potentially important and that its' impact on well being should be treated as an empirical question [House, 1981]. In a later thesis, House and Kahn [1985] make the point that it can be very difficult to discriminate satisfactorily among the different types of support and support providers. There may be considerable overlap as people generally receive multiple types of support from the same persons. Those who give emotional support are the ones who also can be turned to for instrumental aid, information and affirmation or appraisal. House and Kahn

conclude that this does not mean that the analysis of different types of support should be forsaken.

In the present study, the measurement of other types of social support may have revealed some complex interactions. In the case of lung cancer, for example, a patient or their carer who is no longer able to meet family responsibilities as a result of certain aspects of the illness, may benefit from specific help with household tasks (tangible support). The variety of uncertainties and fears that the patient and their family may be experiencing regarding the effects of chemotherapy may benefit from clarification of what is happening (informational support) as well as the reassurance that the feelings and fears are a normal consequence of the illness (validation).

The issue of the value of social support in lung cancer may be more complex than has been considered in this study. Structural and functional measures of support may help to investigate the differential effects of support more thoroughly. In addition, the patient with lung cancer and their carer may be in a position of inequality where they may be thrust into relationships that are not egalitarian or reciprocal as a result of the stigma of the illness. Dunkel-Schetter and Wortman [1982] for example, have reviewed evidence indicating that family members and friends have conflicting feelings about cancer, which may lead them to behave in contradictory ways. The patient and their family may receive subtle mixed messages as supporters try to be reassuring, comforting and give emotional support on the surface, yet, at the same time

exhibit negative non-verbal behaviours. Furthermore, the positive behaviours perceived by the recipient and the providers of that support may be mixed with subtle signs of strain or even occasional negative outbursts. This may lead the recipient to report positive high levels of emotional support which he or she relies upon, but which are also tinged with strong negative inflections.

These hypotheses suggest that a range of different types of support need to be assessed as well as both the positive and negative aspects of these supportive behaviours. This is particularly true in lung cancer where each stage of the patients' management may provide different types of stress. Cohen and McKay [1984] put forward the view that only when supportive relationships provide the appropriate forms of support, will they operate to "buffer" the effects of stress and, in so doing, reduce levels of distress.

Finally, Dunkel-Schetter [1982] advises caution in immediately interpreting a positive correlation between emotional support and distress as evidence of social support causing this distress. She puts forward a plausible alternative explanation, in that patients with poor prognoses (including lung cancer) may make more demands for support than those with better health or a less threatening illness. As a result they may elicit more support but still be exhibiting high levels of psychological distress. As yet, this hypothesis remains untested although a recent study by Rose [1990] partially supports this view. Rose found that if cancer patients

perceived their prognosis to be poor then they had a heightened desire for emotional support from friends and family, but the study was unable to ascertain whether they actually received this support. The results, however, did support the view of distinct types of social support (instrumental and emotional) potentially serving different functions at different times during the illness and, therefore, requiring separate examination.

The impact of lung cancer on the lives of patients and their carers.

The data from the current study suggest that the greatest impact of lung cancer and its treatment on psychosocial adjustment of the patient occurs during the first line management and during palliative therapy. This finding is consistent for the seven domains assessed by the Psychosocial Adjustment to Illness Scale (PAIS). The trend of the scores in these domains indicates a worsening of adjustment problems in the palliative therapy group. This trend is seen in "health care orientation", "vocational environment", "domestic environment", "sexual relationships", "extended family relationships" and "psychological distress". The patients' social environment, however, reverses this effect and a significantly greater impact is seen during first line chemotherapy.

The PAIS domain scores of the three groups of primary carers follows a similar pattern to that of the patients. In all seven

domains the trend is towards a worsening of scores during the time of palliative therapy. The carer is clearly adversely affected by the illness during first line management and palliative therapy. In comparing the PAIS scores of patients and their carers some interesting differences emerge.

In the first line management group, the carer experiences greater problems in terms of "health care orientation" than the patient . In terms of "sexual relationships", however, the patient reports greater difficulties than the carer. This suggests that the carer has a more negative view of the illness, expectations of treatment and attitude to health care than the patient. The patient, however, has experienced a more marked adverse change in sexual interest, frequency of sexual activity, sexual satisfaction and interpersonal "sexual conflict" than the carer during this phase of the illness.

In the follow up surveillance group who have completed treatment, the carer displays greater problems of adaptation in the domains of "health care orientation", "sexual relationships", "social environment" and "psychological distress". The domain of "social environment" assesses the respondents current social and leisure time activities and the degree to which they have suffered impairment or reduction. The domain assesses actual participation and interest in participating in individual leisure activities, family leisure activities and social leisure activities. The domain of "psychological distress" assesses a range of psychological sequelae (anxiety, depression, hostility, guilt, worry, self

devaluation and body image distortion). In the follow up group, the carers show greater adjustment problems than the patient in these areas.

In the palliative therapy group the patient demonstrates significantly poorer adjustment than the carer in terms of sexual relationships. The carer, however, demonstrates significantly greater adjustment problems than the patient in the domains of "social environment" and "psychological distress".

Lung cancer and its treatment has a significant impact on the psychological adjustment of the patient's carer. Whilst a number of studies have used the PAIS to assess the impact of different cancer types on the patient [Baider et al., 1983; Cain et al., 1983; Baider et al., 1989; Gilber and Kaplan de Nour, 1989], the adjustment of the carer has been largely neglected and those which have been conducted have been methodologically weak. In a study of the carers of patients with cancer of the colon [Baider et al., 1989] it was found that the adjustment of male carers was worse than that of female carers on all the PAIS domains. Unfortunately, this study relies on a single assessment and no information is given about the physical symptoms, time since diagnosis or current treatment.

The results of the current study demonstrate a marked impact of the illness on the carer at a time when the patient is not receiving any active treatment (follow up surveillance). It has

been recognised for some time that this is time of uncertainty for the patient [Koocher and Malley, 1981] but is clearly an extremely difficult period for the patients as well.

A number of studies describe the wide ranging effects of other types of cancer on the lives of patients. Fobair et al. [1986] in a study of patients who had been treated for Hodgkin's lymphoma in the past ten years, found that 43 per cent reported difficulties with their leisure and social activities, 42 per cent reported employment problems, 32 per cent were experiencing marital problems and 20 per cent reported decreased sexual activity and interest. Unfortunately this study did not examine the impact of the illness and its treatment on the patients' partner or carer, so the perspective is necessarily limited.

Moynihan [1987], in an elegant study of the psychosocial impact of testicular cancer, examined both patients and their carers. In her sample of 102 patients having undergone treatment for testicular cancer she found that 29 per cent of patients complained of sexual problems, 43 per cent of employment problems with their current job, and 60 per cent of difficulties in obtaining new employment. In the group of carers, only 18 per cent complained of sexual problems and figures for relationship and employment difficulties were not reported. In the group of carers, however, 69 per cent reported that they would have liked additional emotional support. Whilst this study demonstrates high levels of

psychosocial morbidity in patients, the picture for their carers still remains unclear.

A large literature exists which examines the impact of different types of cancer on sexual relationships [Cain et al., 1983; Anderson and Hacker, 1983; Wise, 1987; Gritz et al., 1989; Schover et al., 1989]. A common finding in this literature is that the partner of the patient perceives fewer sexual problems than the patient themselves [Moynihan, 1987; Gritz et al., 1989], which, to some extent, is echoed by the current study in the first line management group and the palliative therapy group of carers. Other areas adversely affected by cancer and its treatment are employment [Houts et al., 1986; Fobair et al., 1986; Welch-McCaffery et al., 1989], insurance coverage [Mor, 1986; Crothers, 1987], and social relationships [Peters-Golden, 1982; Stam et al., 1986]. These studies, while describing the impact on the patient, fail to recognise the wide ranging impact of the disease on the carer.

Recent studies and review papers have commented on the dearth of information relating to the impact of cancer on the psychosocial environment of the carer [Moynihan, 1987; Redd and Jacobsen, 1988; Lewis, 1990]. Yet studies consistently fail to take account of the importance of this fact in their design concentrating exclusively on the patient [Liang et al., 1990]. Paradoxically, however, one of the principal findings consistently reported is the patients' concern of the impact of the illness on the family [Stam et al., 1986; Liang et al., 1990].

The current study not only demonstrates the needs of patients and their relatives using the PAIS scale but also describes a number of other psychosocial needs using the brief interview schedule.

The responses to the questions in this interview schedule provide additional insights into the perceived impact of the disease on the patient and their carer. A significant number of both patients and carers in each of the three groups report that their main worry concerning the illness, is its effect on the family. This concern is consistent at each phase of treatment, whereas specific additional worries are present only at certain times during the illness. It is not surprising, for example, that the predominant worry for patients and carers in the first line management group, is the fear of "not getting better". On the other hand, the main worry of the palliative therapy group is the effect of the illness on the family and the presence of pain and suffering.

The concern regarding the effect of the illness on the family has been reported in a number of previous studies. Stam et al. [1986] found that the most frequent concern in a sample of 449 newly diagnosed patients assessed over a period of one year, was the impact of the illness on the family.

A similar study conducted by Wellisch et al. [1983] in a group of patients who were "housebound" as their illness was more advanced found that their most frequent concern was somatic

side effects of the illness, and, in particular, the presence of pain.

The present study also demonstrates that patients and carers have a number of worries concerning treatment. In the first line group, the most common concern was the side effects of the treatments; in the follow up group, the majority of patients and carers reported that they did not have any worries about the treatment. In this latter group, however, 25 per cent of patients were concerned that they may require further treatment in the future. In the palliative therapy group of patients and carers, the most common concern was the fear that the treatment would be ineffective in controlling symptoms or "in shrinking the tumour".

The effect of treatment on fears, worries and mood state has been reported in numerous studies [Lloyd et al., 1984; Love et al., 1989; Gilbar and Kaplan de Nour, 1989; Christ and Siegel, 1990]. Holland and Lesko [1989] describe the fears and worries that patients experience when they first hear that treatments such as chemotherapy are required. These fears and worries, they claim, are the result of more general societal fears of cancer treatment which have persisted and grown over many years. In addition to the generic or societal fears of cancer treatment patients also develop additional concerns following any previous cancer treatment they may have received. Meyerowitz et al. [1983] found that women who had received chemotherapy for breast cancer still had lingering fears and concerns of the possibility of future treatment up to

two years after the cessation of therapy. Those patients who later received further treatment found that their distress was compounded by the fears and worries developed during their earlier experiences.

Patients, it appears, make some form of "cost-benefit analysis" when considering the effects of treatment. Despite the fact that treatment in the current study was a major source of concern, the majority of patients and their carers hoped that this would enable them to achieve long term control of their disease as well as relieving troublesome symptoms. These types of hopes and aspirations presumably help the patients and their families cope with the fears, concerns, and rigours imposed by chemotherapy and radiotherapy. These hopes and aspirations are probably formed at the stage of diagnosis based on information imparted by members of the health care team.

When reporting the actual aims of treatment a surprising perception was noted. In the first line group the majority of patients and carers recognised that the aim of treatment was to control the disease (a correct perception). In the follow up group the majority of respondents correctly identified the monitoring of progress as the aim of treatment. In the palliative therapy group, 35 per cent of patients perceived the aim of treatment as being "curative". In contrast to this only 12.5 per cent of carers responded in this way. Fifty two and a half per cent of carers correctly reported that the aim of

treatment was to relieve troublesome symptoms, whereas only 25 per cent of patients responded in this way.

Similar findings have been reported by Mackillop et al. [1988]. In this study, 100 patients with advanced cancer were interviewed, 33.3 per cent believed that the therapeutic intention was to cure their disease, whereas, in reality, the aim was palliation. Whereas the majority of the physicians (90 per cent) treating these patients were not aware of this misunderstanding and felt that they had accurately informed the patient of the extent of the disease and the aims of treatment.

An earlier study by Eidinger and Schapara [1984] interviewed 190 patients with metastatic disease. Only 55 per cent of this sample were aware that their cancer had spread and only 48 per cent knew the location of their metastases. The group were receiving supportive care only or palliative treatment, yet 37 per cent reported that the goal of treatment was to "cure them". In this sample of patients, however, 84 per cent reported being satisfied with the amount of information they had received from their physician with regard to their disease and its treatment.

These studies, including the present one, consistently report that about one third of patients "misperceive" the aim of treatment. In the present study, there is no objective assessment of the information that patients were actually given. Certainly the prevalent view in the department was

that patients were told honestly and openly the facts about their illness and its treatment.

Perhaps then, this 30 per cent of patients represent those people who utilise "denial" as a coping strategy. Cassileth et al. [1980] has reported that some patients who are seriously ill, never fully acknowledge the gravity of their situation, no matter how well it is explained to them. Some authors have regarded denial as an adaptive process which enables the individual to cope with an otherwise untenable situation [Hacket and Cassem, 1970; Taylor, 1983]. Unfortunately, in the present study it is not possible to discern the relative contributions of failed communications and/ or denial in the observed effect.

Both patients and their carers report a significant impact of the illness and its treatment on their personal lives. The effect is clearly different for the patients than for the carers. In the first line management group, 50 per cent of the patients reported that the illness was sometimes on their mind, 10 per cent found it was always on their mind, and 37.5 per cent reported that they tried not to think about it. The carers, on the other hand, were more evenly distributed in their responses: 45 per cent said it was on their mind all the time, 27.5 per cent that was sometimes on their mind, and 25 per cent tried not to think about it.

In the follow up group 52.5 per cent of the patients reported that it was sometimes on their mind but 25 per cent reported

that it was on their mind all the time and only 10 per cent **tried not** to think about it. In this group, 12.5 per cent reported that they **did not** think about it. The majority of the carers, however, reported that the illness was on their mind all the time (65 per cent). The carers clearly found themselves preoccupied by the illness even when the patient was not receiving treatment. The same number of carers as patients in this group reported that they **did not** think about it (12.5 per cent).

In the palliative therapy group further support for the view that some patients may use denial as a coping strategy can be found. Almost a third of patients reported that the illness was on their mind all the time and a similar number reported that they **did not** think about it. In contrast, the carers reported that the illness was either on their mind all the time (57.5 per cent) or on their mind some of the time (30 per cent) and only a small number reported that they **did not** think about it (5 per cent).

In addition to the amount of time that patients and carers give to thinking about the illness, they also reported that they were usually prepared to discuss the illness with others. In the three groups of patients and carers, the majority reported that they were prepared to talk openly about the illness or, that they would talk to selected people about it at selected times. Few of the carers reported that they would avoid the subject, but the trend among the three groups of patients was for a significant number to adopt this latter approach. In the first

line management group 12.5 per cent avoided the subject, in the follow up group 17.5 per cent, and the palliative therapy group 22.5 per cent. Again, this avoidant coping strategy may be a form of "denial".

Few studies have looked at these specific issues in any systematic way for either patients or carers. Howell [1986] studied the spouses of patients with advanced cancer receiving supportive care only. She reported that over half the carers experienced frequent unpleasant thoughts about the illness. Wright and Dyck [1984] interviewed the next of kin of 45 cancer patients at three points during their illness: diagnosis; recurrence; and during the terminal stages. They found that in the family members, a significant number felt that it was important to talk about the illness with others. Vachon et al. [1977] compared the problems experienced by widows of cancer patients with the problems encountered by the widows of cardiac patients during the final illness. The widows of the cancer patients were preoccupied with the illness and experienced a greater sense of helplessness and impotence than those of the cardiac patients.

Most patients and carers in the current study had access to others who could offer them help and support. Both described a range of other people or institutions providing this. A significant number identified the church as their main social support. This has been reported in a number of other studies as playing a significant supportive role for patients with cancer [Carey, 1974b]. Religious affiliation has also been shown

to reduce anxiety in patients following their diagnosis and during treatment [Yates et al., 1981].

The current study demonstrates the interrelatedness of patient and their carer and the mutual supportive functions they offer each other. It also supports other studies which have identified family members as being the primary source of psychological support for the patient with cancer [Guiacquinta, 1977; Northouse, 1981; Stolar, 1982]. This is often viewed from a "family systems perspective" which describes the effects of an illness such as cancer as reverberating throughout the family [Minuchin, 1974; Northouse, 1988b].

Whilst many of the effects of the illness and its treatment on the patient and their carer are negative, there are some positive effects. The majority of patients and their carers perceived that the illness had brought them closer together. A similar finding was noted with respect to communication: the majority of patients and their carers perceived that communication between them had increased. These results are consistent with those of Leiber et al. [1976] who demonstrated that patients and their carers reported closer relationships following their diagnosis.

During certain phases of the illness and its treatment, a substantial percentage of patients and their carers (in the current study) perceived that they had become more distant and that communication between them had decreased. In the

first line management group, for example, about 20 per cent of patients and their carers reported this effect. Interestingly, in the follow up group of carers about 25 per cent reported the same perception. The latter group are of interest as carers clearly find the follow up surveillance period difficult to cope with. They display high levels of anxiety and report significant problems related to psychosocial adjustment.

Communication problems have been reported between patients and their carers in other studies. Jamison et al. [1978] found that 89 per cent of patients before mastectomy reported little or no discussion of emotional concerns with their spouse. These researchers also found that 87 per cent of patients reported communication problems while in hospital and 50 per cent continued this pattern at home. Other researchers have commented on communication difficulties during other stages of the illness. Checkryn [1984] in a sample of patients whose cancer had recurred found that couples seldom talked about the recurrence of the disease or, only discussed it to a limited degree. Continued communication difficulties have been reported in the terminal phases of cancer [Vachon, 1977; Krant, 1977-78; Hinton, 1981], and estimates indicate that approximately 60-78 per cent of couples never discuss death with their partner at all [Krant, 1977-78; Hinton, 1981]. Krant and Johnston [1977-78] reported significant difficulties with communication between patients and carers during the terminal stages of the illness. Patients in the latter study, however, were receiving supportive care only, whereas the

patients in the present study with advanced cancer were receiving palliative treatment to alleviate symptoms.

Certainly, in the current study fewer patients report a reduction in communication than can be found in the literature: the majority of patients and their carers report an increase in communication. This may be due to: specific aspects of lung cancer in that survival tends to be around 12 months following diagnosis (a less protracted illness than in most studies); or may relate to the inclusion of patients in clinical trials. As a result patients were closely monitored and had regular contact with the health care team which may have indirectly helped communication between the patient and the carer.

The importance of communication has been stressed in other studies. Investigators have found that open communication between partners is a significant predictor of adjustment following the diagnosis of breast cancer [Baider and Kaplan de Nour, 1984; Northouse, 1988b]. The latter researchers have also reported that higher levels of family expressiveness have been associated with better adjustment for mastectomy patients and their husbands. Vess [1985] has found that open communication has also been associated with better negotiation of altered family roles following a cancer diagnosis and Cohen et al., [1977] have found that families with open communication styles have a better adjustment following

bereavement. Whilst the current study does not examine adaptation and communication, the importance of the latter is clearly vitally important in the arena of cancer care.

There are, however, still aspects of communication which require further study. Vachon [1977] found that 59 per cent of the widows in one study reported that they had not discussed death with their husbands, and this was found not to adversely affect their adjustment. Thorne [1977] reported that some people actively choose a communication style which inhibits the discussion of the illness. Orr [1986], in contrast to other studies, found that breast cancer patients with an "open" communication style had poorer adjustment than those who avoided communication about their feelings towards their illness. On the other hand, those patients who sought facts about their illness from the health care team had a better adjustment in the form of reduced distress. The issue of communication therefore requires a considerable amount of further research.

The present study demonstrates the range of perceived effects that lung cancer and its treatment can have on the family. In the first line management group and the follow up group the majority of patients and their carers reported that the illness had led the family to have a greater appreciation of each other. In these two groups, however, a significant number of respondents reported that the illness had either caused distress, or had brought them closer together. In the palliative therapy group, the majority of patients and carers reported

that the main effect of the illness was to have caused distress but that a significant number reported a greater appreciation of other family members. Interestingly, only a small number of respondents reported that the illness had caused division in the family. These data broadly support a range of other reports which indicate that families are often brought closer together by cancer [Leiber et al., 1976], creates distress in the family unit [Checkryn, 1984; Cassileth et al., 1985], and leads to a change in values and priorities among family members who become less interested in "trivia" and more interested in spending time together [Cooper, 1984].

Patients and their carers in the current study report significant decreases in their social interaction with family and friends at all stages of the illness process. In addition, a significant number report decreasing leisure activities throughout the illness. Few patients and relatives report an increase in these activities, although a number reported that there had been no change in them. Other studies have reported a marked decrease in the patients' social and leisure activities [Maguire, 1981; Fobair et al., 1986; Moynihan, 1987]. A small number of studies have commented on the impact on the social and leisure activities of the carer. Haggmark et al. [1987] reported that the relatives of patients with cancer tend to reduce their contacts with friends and family outside the home, which in turn can lead to distress. These researchers offered relatives the opportunity to increase their social activity patterns and, in so doing, increased the ability of these

relatives to deal with their feelings of hopelessness and distress.

Howell [1986] in a study of 30 spouses of patients with advanced cancer (mainly lung cancer) found that lifestyle changes were the most frequently reported problem area.. The specific problems identified were the lack of social interaction outside the home and being confined to the house for long periods. This created difficulties for spouses as it limited the opportunities for the ventilation of distress to other people and feelings of inadequate support began to develop.

Oberst and James [1985] found that lifestyle disruption was a concern for over 50 per cent of spouses of newly diagnosed cancer patients following surgery. Spouses reported that their employment and household schedules were altered, arrangement for child care changed, and social activities were curtailed. During the period of the study (three months) these changes in lifestyle persisted.

The effects of illness on the carer has most often been reported in relation to psychiatric illness or dementia [Fadden et al., 1987b]. These studies report profound effects of an illness such as depression on the lives of the carers. Fadden et al. [1987], in a study of the carers of 24 depressed patients, found that 71 per cent reported a reduction in social activities. These carers reported feeling socially isolated and experiencing periods of low mood themselves. The incidence of

reduced social and leisure activities in these groups (depressed patients versus cancer patients) may be similar but the reasons for this are completely different. In the cancer patient the carers' activities are reduced because the patient is physically unwell [Howell, 1976] and in the psychiatric setting it is reported to be either due to the patient being regarded as "unsafe" to be left alone or to the stigma that society attaches to mental illness which causes the carer to limit their social interaction with others [Fadden et al., 1987]. The important point in this comparison is that the plight of the carer in psychiatry is well documented [Brown and Harris, 1978; Falloon et al., 1982; Fadden et al., 1987], in contrast to the plight of the carer of the cancer patient.

Most of the carers in the current study clearly perceive themselves as having a specific role to play in helping the patient cope with the illness and its treatment. In the first line and follow up surveillance groups the majority perceived their role to be helping the patient fight the disease (55 per cent and 45 per cent respectively) and about a third perceived their role to be helping the patient come to terms with their illness. In the palliative therapy group the picture changes: only 12.5 per cent reported that their role was to help the patient fight the disease and 42.5 per cent reported their role to be helping the patient come to terms with it whilst 37.5 per cent reported that their role was to support the patient. This suggests that the carer understands the severity of the situation during palliative therapy as their perceptions of role have changed. At the same time the carer may experience

conflicts if they perceive themselves as failing to fulfill these roles. Vachon [1977] reported that carers often experience feelings of despair and isolation as they watch the patient suffer and feel helpless if they do no know how to help them or fail to live up to their own expectations of themselves.

Spouses of patients with lung cancer have been found to report feelings of helplessness as they watch their partners deteriorate [Cooper,1984]. Compared to patients with other serious illnesses, they report a greater sense of impotence and despair with their situation. This occurs because with other illnesses, such as heart disease, the spouses can be active, for example by attending to the patients' diets and their activity needs, whereas the spouses of cancer patients feel that there is very little they can do to help the patient [Vachon,1979].

Although the carer may perceive themselves as having a role to play in the patient cope with the illness, they may find themselves overwhelmed with other demands. Cancer, as described earlier, imposes a wide range of stressors on the carer. Each stage of the illness and its treatment introduces its own fears, worries and stress [Weisman, 1979]. These may include the existential threat of cancer and its associated images of pain and death, suffering and distress from treatment, effects on lifestyle, uncertainty of the future and impending death [Lewis, 1990]. Wright and Dyck [1984] found that the four most commonly cited concerns of family members were: fear of the future; the problem of obtaining information; the stress of watching the patient suffer and the

stress of waiting. Given this range of problems, the carer may not be able to fulfill all the expectations they may have of themselves.

Clearly the current data does not elucidate whether carers are able to realise their role expectations in the patients' illness and its treatment. Role conflict, however, may be an area that would benefit from further research and investigation.

The relevance of the findings of the current study to clinical practice

The current study demonstrates the impact of lung cancer and its treatment on the psychological state of the patient. There is clearly an adverse effect on the mood state of certain patients and a range of factors have been shown to contribute to this distress. In particular the mood state of the patient's carer has been shown to have a significant contribution to this.

These results suggest the need for psychological intervention with these patients. This is not a novel suggestion and has been put forward by researchers in the past with respect to the psychological impact of other types of cancer [Maguire, 1980; 1984]. In the area of lung cancer, however, there have been few studies examining the psychological impact of the disease. Bernhard and Ganz [1991b] in a review of the area recently commented, "to our knowledge, there are no comprehensive reviews on psychiatric distress in lung cancer

patients"(p481). They would like to see more research conducted, particularly research concerning the effects of psychological therapy in these patients.

There is a comprehensive literature concerning the impact of a range of psychological interventions with cancer patients (as well as psychotropic drug use) [Derogatis et al., 1979; Jaeger et al., 1985]. Gordon et al . [1980] compared standard hospital care (i.e. no formal psychosocial intervention) with supportive psychotherapy and found a number of benefits stemming from the latter approach. The psychotherapeutic intervention was associated with a more rapid decline in negative affect and a higher level of general activity.

Bridge et al. [1988] in a six week randomised controlled trial of 154 women with breast cancer examined the impact of relaxation and imagery alone and in combination, on anxiety. At six weeks after the start of the interventions, it was found that mood disturbance was significantly less in both intervention groups than in the control group. Women in the combined intervention group showed a greater improvement in mood than those receiving relaxation only.

More recently, interest has centred on a newly developed cognitive-behavioural treatment, adjuvant psychological therapy (APT). The method has been described and evaluated by Greer and Moorey in a series of papers [Greer and Moorey, 1987; Greer, 1989; Moorey and Greer, 1989; Greer et al., 1991]. Most recently Greer et al. [1991] have shown that even a small

number of sessions of therapy can reduce anxiety and depression as well as promoting positive changes in mental adjustment to cancer.

Counselling is another intervention that has been used. Attempts to evaluate its' efficacy, however, has suffered from a range of problems related to its definition and assessment [Fallowfield, 1988; 1991]. A number of studies report its' use, particularly in women with breast cancer [Maguire, 1980a], although interpretation of such studies can be very difficult for the reasons specified previously.

Clearly then, a range of psychological therapies exist which can be used to improve the quality of life of patients with cancer. The current study suggests that a proportion of patients at all stages of the illness and its treatment might benefit from such input.

Perhaps the most striking findings is the effect of the illness and its treatment on the patient's carer. Not only are there profound effects on anxiety and depression in this group but there is also a significant impact on lifestyle when compared with the patient.

This suggests that the carer should be at least screened for the presence of psychological disturbance with a view to intervening with those people who show high levels of distress. The same psychological techniques described previously could be used with carers. There is no reason why

APT, for example, could not be used with them as the therapy was developed from the cognitive therapy techniques described by Beck for use with a wide range of emotional disorders [Beck, 1976].

The implications of the data presented in this thesis suggest that the patient and their carer cannot be viewed in isolation from each other as they have a significant impact on the other's mood state. As Northouse [1984] states, "The reactions of the cancer patient affect family members, and family members' reactions affect the patient.....families are in a dynamic state of change, constantly responding to events inside and outside the family" (p216). The patient and their carer therefore may need to receive some form of psychosocial intervention.

Many reviews of the literature concerning the impact of cancer on the family conclude that the primary carer is neglected in terms of research and psychosocial interventions [Freidenbergs et al., 1981-2; Naysmith et al., 1983; Keitel et al., 1990].

The current study also demonstrates that the illness has a significant adverse effect on the carer's lifestyle when compared to the patient. Again, this is an area which can be addressed by the health care team in a number of different ways such as social work, psychology and self help groups.

Health care professionals may find it useful to view the illness of lung cancer as a "process". This process is composed of a

number of different stages and each can be viewed as a series of stressors which may interact to promote and/ or maintain distress in both patients and their carers.

This study suggests that the value of social support in adjustment is complex. It has been noted that health care professionals often regard the presence of a confidant(e) as very positive and may, therefore, reduce their attention to the patient and their family [Veiel, 1985; Lichtman and Taylor, 1986]. This study indicates that this may not always be the case and the source of support may need to be assessed more fully.

The patient's carer is especially vulnerable to the latter effect and particularly prone to being overlooked if they describe themselves as having "adequate social support" [Lichtman and Taylor, 1986]. Yet, as described here, the presence of social support may not always be beneficial to that person. In addition, social support may change in response to certain variables such as symptoms of the illness and may need continual assessment and monitoring, particularly as the illness progresses.

More comprehensive assessments are, therefore, required in clinical practice of both patients and their carers. These assessments need to be wide ranging and be continually updated over time.

The current study evaluated

The current study of the psychosocial impact of lung cancer on patients and their primary carer has improved on many of the methodological shortcomings of other studies in this area. The research design has used a homogeneous group of cancer patients and assessed them at different points during the illness and its treatment. In addition, the patient's primary carer has also been included in the study at the same time points. The assessments have used standardised, well validated, reliable scales, some of which have been specifically designed for use with patients suffering from a physical illness such as cancer.

The current study could be seen as a pilot study and a number of improvements could be made. The number of subjects in each group is relatively small and could be increased. The sample size reflects the total number of suitable patients available at the time the study was being carried out in the department.

The design is, as far as can be ascertained, unique in the way that the "process" of the illness is represented. This suggests that until a cross validation study of the same design is carried out the results must be viewed tentatively.

The subjects in the current study may not be representative of lung cancer patients generally. All the patients were taking part in a trial of specific combination chemotherapy regimens.

This means that they received careful follow up care and monitoring in the department and may not represent the typical picture of patients with lung cancer.

This study also made no attempt to control variables beyond those specified: it was designed as a descriptive study and all suitable lung cancer patients within the department were included. This lack of control of variables may weaken some of the findings and is an obvious criticism of the current research design. Future studies in this area would benefit from more rigorous control of variables and better matching of patients in the groups (first line management group, follow up group, and palliative therapy group). For example, the group of patients are not exactly matched for age and the group of carers are quite diverse with few friends and children represented. Greater control of some of these variables may give a greater understanding of the impact of the illness.

The three groups selected have been used to represent the "process" of the disease and its treatment. The implicit assumption that is being made, however, is that the subjects in these groups have undergone similar experiences. This assumption cannot be validated and may not be accurate. The study would have been enhanced by a longitudinal design that followed patients and their carers through the "process".

The current design is unable to assess change as it provides "snapshots" at different time points. The data is able to provide some insights into the impact of the illness at these

times but is not able to detect any pattern of effects between these times. A longitudinal study may have given a clearer picture of the changing psychosocial impact of the disease over time.

The study first assesses patients at the midpoint of their first line management. It is not possible, therefore, to know how many patients and their carers were depressed or anxious before the diagnosis of lung cancer was made. The assumption that has to be made with the present data is that the mood state of the subjects is related to the diagnosis. Hughes [1985b], however, in a study of 134 patients with lung cancer found that 22 (16 per cent) fulfilled the criteria for depressive illness. In this group, 13 of the 22 patients gave a clear history of having been depressed before their physical symptoms began, apparently in reaction to life stress unrelated to their cancer. In the current study the number of respondents experiencing clinical levels of depression and/ or anxiety before their diagnosis is unknown.

A control group may have added an important dimension as the results are difficult to place into a contextual framework. Such a control group may have included patients with a serious, non-malignant chest disease such as chronic obstructive airways disease (chronic bronchitis, or bronchial asthma). These illnesses are also recognised as having marked psychosocial sequelae for the patient and their family [Sandhu, 1986] and may have proved to have been an interesting comparison group.

On the other hand, some researchers consider that the introduction of a control group into such a study unnecessarily introduces a source of bias [Bloom and Ross, 1982]. Comparing distress in patients with lung cancer with distress in other patients with chest disease may reveal marked differences on some preselected assessment tool. The interpretation of this type of result, however, requires the comparison of each group with appropriate normative data rather than each other. In fact, Bloom and Ross [1982], in reviewing the field of psychosocial oncology conclude that;

> " Using between subject designs to look for differences between cancer patients and other groups of people is that the specific questions asked are likely to be motivated toward finding that cancer patients are indeed suffering more and differently.....Use of cancer-specific items or instruments may bias results in such a way that need for support programmes will be a logical inference of the study. Researchers working with individuals in the health care system (not only those with cancer) would do well to avoid having to demonstrate that one group of patients is suffering more than another." (p260)

There are, therefore, arguments for and against using control groups in a study of the type described in this thesis. Bloom and Ross advocate the definition of a clear question to be answered in a specific group of cancer patients, rather than the introduction of a group of patients with another illness for comparison.

The issue of the measurement of social support in this study could be criticised. In retrospect, the single measure of perceived emotional support from family and friends could be regarded as inadequate. Additional measures assessing other dimensions of social support could have been included. It must be remembered, however, that the current study was testing a specific hypothesis concerning emotional social support and that the addition of extra scales or questionnaires would have confused and complicated the research design as well as making the assessment procedure unwieldy, thereby reducing compliance. Further research in the area of social support in oncology is dealt with in the next section.

The current study examines the impact of lung cancer on the "primary carer" only. The purpose of concentrating on a designated person was to try to replicate other studies in this area [Plumb and Holland, 1977; Baider and Kaplan de Nour, 1984; Goldberg et al., 1984; Cassileth et al., 1985; Oberst and James, 1985] who utilised the primary carer or the patients' spouse. The study may have benefited from the inclusion of other family members in the design such as children, brothers, sisters or parents. Studies that have attempted such ambitious designs have, on the whole, been singularly unsuccessful in their task [Northouse, 1988b]. These designs have typically been difficult to implement in a society where families are often geographically separated and where other family members, particularly children, are regarded as tangential to or even excluded from the patient's treatment plans. To include these other family members in the current study may

have been extremely difficult and have led to a reduction in the quality and quantity of data collected.

As far as possible this study has utilised standardised, valid and reliable assessment tools. The assessment of symptoms and side effects in the patients was undertaken using a scale developed in the Edinburgh department [Cull and North, 1988]. This scale has been utilised in a number of "in-house" studies of lung cancer patients and at the time that the current study was being planned, its use was thought to be appropriate. Since this time, however, other scales have been developed, in particular the Rotterdam Symptom Checklist (RSCL) [Haes et al., 1983]. This scale has become widely used since the latter half of the 1980's and assesses both physical and psychological symptoms. The RSCL has good reliability and validity and is recommended as the tool best suited to assess the key dimensions of quality of life [de Haes et al., 1983; van Knippenberg and de Haes, 1988; Maguire and Selby, 1989; de Haes et al., 1990]. If details on the reliability and validity of the RSCL had been more widely available at the planning stage of the current study it would have been a valuable tool to include.

The Hospital Anxiety and Depression Scale [Zigmond and Snaith, 1983] is an assessment tool designed specifically for use with patients who are physically ill. The tool has proved to be very robust across studies and has been shown to be composed of two distinct but correlated factors, anxiety and depression [Barczak et al., 1988; Maguire and Selby, 1989;

Moorey et al., 1991]. The scale performed very well in the present study and patients and their carers found it easy to understand and complete. One of the items, however, concerns the statement "I feel as if I am slowed down". The response most often scored by patients for this item was "Nearly all the time" , this was particularly noticeable in those receiving chemotherapy or palliative radiotherapy.

This item has caused some concern as it may reflect the somatic effects of the illness and its treatment rather than psychological distress. This concern has been investigated by Ibbotson et al. [1988] This study suggests that minor adjustments to the HAD "cut off" scores may be required (depending on the stage of the disease that the patient has reached) in order to improve the sensitivity and specificity of the scale. Ibbotson et al. [1988] compared the HAD with the General Health Questionnaire and the Rotterdam Symptom Checklist (RSCL). All three scales were evaluated by comparison with the Psychiatric Assessment Schedule, a gold standard. The data suggested that the HAD scale produced the best overall performance but the RSCL performed better as a screening instrument for patients with “stable disease”.

More recently this issue has been investigated by Hopwood et al. [1991a]. They compared the HAD and the RSCL in women with advanced breast cancer. It was found that the scales detected different groups of patients as “cases”; only 43 per cent (of “cases”) being detected by both questionnaires. Hopwood et al. conclude that "these questionnaires are not yet

sufficiently robust in their psychometric properties to give precise prevalence rates" (p352). In a refinement of this study, Hopwood et al. [1991b] found that both scales were suitable for use as screening instruments in the detection of psychiatric morbidity. They suggest that both warrant refinements to their "cut off" scores to improve their sensitivity and specificity. They conclude that;

> "In using either questionnaire as a screening instrument careful preparation is advisable: sensitivity, specificity and cut off values should be checked, and the predictive value should be calculated according to the known prevalence of affective disorder in the population of patients to be screened. Used in this way, these two instruments will provide a valuable clinical tool in the detection of psychological morbidity." (p355)

This area requires extensive further investigation particularly in relation to different treatments and specific diagnostic groups. In this way, the requirements of Hopwood and her colleagues for the use of scales in cancer care would be satisfied. At the current time the HAD scale continues to be used with the thresholds recommended by the authors and as a result these have been retained and utilised in this study as the current state of the research data is insufficient to warrant their adjustment.

The study design was developed to provide a comprehensive picture of the psychosocial impact of lung cancer and its treatment. In conducting a study of this type it is necessary to work within the constraints imposed by the clinical environment and the subjects. The initial design, for example,

was modified from a longitudinal one, in response to the carers' predicament. A further refinement that may have yielded a more representative picture of day to day life would have been to interview some of the respondents in their own homes, particularly in the follow up group. This was not possible as the patients were drawn from South-East Scotland and the Borders, a large geographical area. This resulted in all the interviews being conducted in hospital wards or the outpatient clinic. One could argue that this may have artificially increased anxiety and depression scores as it has frequently been recorded that visits to hospital and out patient clinics can have this effect [Schag and Heinrich, 1989]. None of the scales used in this study were concerned with the immediate time scale: all concerned with emotions or difficulties that were experienced during the previous week or previous few weeks. These instructions were impressed on the respondents and the assumption has to be made that this had been understood and followed.

The clinical situation may, however, have led to contamination of scores but not to such an extent that all the results could be dismissed. The group most susceptible to this effect would have been the follow up group, who only visited the clinic once a month. In contrast, the other two groups would have had frequent contact with hospital clinics and departments thus leading to an adaptation to the clinical environment and possibly a reduction in the anxiety that this provokes.

The final way in which the study could have been improved would have been to have included a group of bereaved carers. This would have completed the picture of the "process" of the disease and provided some important insights into the long term effects on the carer. Unfortunately, this proved to be untenable due to the geographical spread from which carers came and because of the very vulnerable and distressed state of this group. It was felt by the researcher to be unethical to assess such a group on a "one off" basis without offering them further opportunities for ventilation of emotions and support. Such a situation may have been avoided if the study had been longitudinal and a rapport had been developed over the course of the illness.

The current study has provided some important and valuable data regarding the psychosocial impact of lung cancer and its treatment. The data concerning the impact on the carer are particularly important and carry with it a range of service implications. The interaction between the psychosocial variables of patient and carer is also very revealing and again has implications for service provision. Finally, the data suggest that the effects of social support may be more complex than was previously thought and warrants considerable further investigation.

The current study has described a difficult and sensitive area of cancer care overcoming many methodological problems of previous studies to produce a coherent piece of work. Respondent fatigue and non-compliance have been overcome

and the essential elements of the disease/ treatment "process" have been investigated and described to form the basis of future research studies in this area.

Future Research Directions

The current study represents a pilot study in this area of psychosocial oncology and the results must be treated with some caution. The results of the project suggests a number of avenues for further research in this area.

The study would benefit from a replication using a similar design but with a much larger sample. Such a cross validation study would be essential before embarking on the provision of services based on the current findings.

The subjects in this study were entered into clinical trials and as a result may have received a different type of health care than lung cancer patients who are not participating in a clinical trial. Future research projects may give greater insights into the impact of lung cancer if non-trial patients and their carers were studied in order to compare the two experiences. Researchers have for some years speculated that the care and attention given to patients in trials is quite different to that offered to other patients [Mackillop and Johnston, 1986; Mackillop et al., 1988], this question therefore should be addressed.

The present study suggests that the patient's carer experiences high levels of anxiety and depression throughout the course of the illness and its treatment. The study, however, is unable to provide detailed information into the nature of this distress in terms of behavioural changes and effects on cognitions. This information would be extremely important in understanding the carer's plight. It would also aid the development of intervention strategies particularly if the pattern that they follow over the course of the illness could be described.

The role of information in patient adjustment to a diagnosis of cancer has been thoroughly researched [Feldman, 1978; Weisman and Worden, 1980; Hogbin and Fallowfield, 1989]. This topic, however, has not been examined in relation to family members, despite the fact they place a high priority on obtaining full and accurate information about the patient's condition [Wright and Dyck, 1984; Northouse, 1988b; Liang et al., 1990]. Family members often feel that they are denied access to information by nursing and medical staff which merely serves to exacerbate their distress [Bond, 1982; Bond, 1982b; Dyck and Wright, 1986]. The role of information, therefore, in the adjustment of the patients carer is a necessary and important study to undertake.

An intervention study with distressed carers would be important to undertake and a range of therapeutic techniques are available for evaluation. Unfortunately, these studies can sometimes be complicated and costly to carry out, particularly

if they are randomised and controlled. The feasibility of this would need to be carefully considered and may require considerable co-operation from a number of professions such as psychiatry, psychology, social work and nursing.

Social support and its role in adjustment to cancer has been shown to be a complex issue. Cancer can be seen as presenting multiple stressors which are interwoven and which change over time. Because of the complexity of these stressors, an evaluation of the role of different types of social support throughout the illness is required. Such a study is necessary because to examine a single form of social support is clearly inadequate.

This would necessarily entail an investigation into the negative as well as the positive qualities of social support. The majority of studies concentrate on the positive qualities [Funch and Mettlin, 1982; Bloom, 1982; Bloom et al., 1984; Vachon, 1984; McIvor et al., 1984] yet there are clearly negative aspects to be considered as well [Blau, 1964; Revenson et al., 1983] which are not fully understood. The present study suggests that there may be negative aspects to social support yet it has not been possible to investigate this finding with complete satisfaction.

A future study of this type may be able to describe the mechanisms by which social support acts. The prevalent debate concerning the "main effect" versus the "buffering mechanism" has not been resolved adequately. Future

research, testing the effectiveness of specific support resources in response to specific stressors would help to clarify the operative mechanisms of the concept. These studies need to be based on clear theoretical models and a clear understanding of the stressors being faced.

Longitudinal research designs in this field are essential as the changes in social support over time have never been researched fully [Wortman, 1984]. In so doing, the determinants of social support could be investigated as there is evidence to suggest that social support is affected by such factors as age, gender, disease status and symptomatology [Vaux, 1985; Dakoff and Taylor, 1990; Willey and Silliman, 1990]. Such a study would have implications for enhancing or manipulating the type of social support that patients and their families receive. It may also reveal why, for some people, social support is not always provided, as well as the "cost" of "giving" social support by the provider [Shumaker and Brownell, 1984].

A question central to all these studies is the use of appropriate social support scales. Kobasa et al. [1991] suggest that "there would probably never be a single social support scale that had all of the dimensions required by existing theoretical and methodologic considerations" (p789). This assertion suggests that it is very important to select suitable scales, particularly if the aim of the study is to assess the contribution of different types of social support in facilitating adjustment to cancer. The selection of tools, with satisfactory psychometric properties, is

one of the most important considerations in any study of social support [Wortman, 1984].

Social support from family and friends has been shown to reduce psychological distress, resulting from a stressful event [Procidano and Heller, 1983]. Such a clearcut finding was not forthcoming in the present study. In fact, it has been suggested that social support from family and friends may itself lead to distress, particularly if the providers of that support are distressed themselves. This explanation is a tentative hypothesis which requires further investigation. In particular, the psychological state of these support providers needs to be assessed. In addition, a comparison of the efficacy of support provided by family and friends and the support provided by "strangers" such as health care professionals or people outside the immediate family is essential. Dunkel-Schetter [1984] for example, reports that emotional support from family and friends is regarded as the most useful source of support by the patient, yet this type of social support may inadvertently maintain distress in the patient.

Cohen and Wills [1985] suggest that these perceptions of the most useful sources and types of support require further investigation themselves. The authors would like to investigate the source of perceptions of adequate support. They suggest that these perceptions must be based on actual social exchanges and supportive transactions, either personally experienced or observed, yet there is little direct evidence of these exchanges. Cohen and Wills suggest that useful future

research should attempt to elucidate which aspects of the social environment are perceived as supportive, and how and where supportive transactions occur. This, they state, will aid the understanding of the mechanisms of social support in the general process of coping with stress.

This theme is expanded by Kobasa et al. [1991] who put forward the view that future research in this area should be concerned with the larger issues of the social environment. In particular, they recommend that future research be conducted in populations beset by poverty with poor social support and health care networks. Such an undertaking would need to be on a vast scale, supported by large funding bodies and, in reality, would be moving the focus of social support from the "micro" level to the "macro" level, involving whole communities. Such an undertaking would require multicentre collaboration from a large number of highly motivated institutuions. In the current economic and political climate such a research project is not feasible.

A competing area of research has arisen recently in assessing the impact of perceived social support on immune function. Levy et al. [1990] have reported that breast cancer patients with high levels of perceived social support were found to have higher levels of "natural killer cell activity" than with those with low social support. Related to this, Baron et al. [1990] have reported that the spouses of cancer patients with high levels of social support also showed higher levels of "natural killer cell activity". These studies both suggest that

individuals experiencing a severe and chronic life stress showed evidence of a more efficient and effective immune system if they had high levels of perceived social support.

Findings such as these, if replicated, may have important implications for the role and mechanisms of social support. These effects would not only help to explain adjustment to stress but would also have important implications for the role of social support in promoting and maintaining health. This research is, as yet, in its infancy and requires a considerable sustained research effort in the years ahead.

Future research in this area must aim at a greater understanding of the experience of the cancer patient and their family throughout the course of the illness. In addition, emphasis must be focussed on ways of reducing distress and improving their quality of life. Social support is one area where further investigation and intervention is needed, as the concept, at present, is still at an early stage of understanding. As Kessler et al. [1985] so aptly point out;

> "to date, studies of specific life crises have not realised their potential, either as a means of increasing our basic understanding of fundamental support processes or as a foundation on which interventions can be built. Most studies of this sort have simply attempted to show that support is associated with subsequent adjustment without linking support to other variables that might help elucidate causal processes. For progress to be made, the advantages of this research design will have to be more fully exploited in the future." (p545)

Cohen and Wills [1985] go even further in the conclusion to their review on social support;

> "New research in this area will have important implications for the understanding of stress and coping, the determinants of psychological adjustment and physical health, and the social structure of communities. Such knowledge will serve to strengthen the supportive aspects of informal helping networks and may provide a basis for a new partnership between lay helping resources and professional helpers. This work, we think, will contribute in many ways to the well being of individuals, families and the larger society." (p353)

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Appendix 1

LOTHIAN HEALTH BOARD NORTHERN GENERAL, ROYAL VICTORIA AND WESTERN GENERAL UNIT

Regional Department of Clinical Oncology

Please direct all correspondence to:
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RADIATION ONCOLOGY UNIT

Consultants:
Dr G.L. Ritchie
Dr G.A. Newaishy
Dr A. Rodger
Dr R.H. MacDougall
Dr V.J. Cowie
Dr G.C.W. Howard

Hon. Consultants:
Prof. W.J. Mackillop
Dr A. Gregor

Your Ref
Our Ref
Date
Enquiries to
Ext. No.

INFORMATION FOR PATIENTS AND RELATIVES

In this unit we feel it is important not simply to treat disease but to care for the whole patient and his/her family. This by necessity involves understanding how an illness and its treatment affects the patients and those closest to that person.

In order to achieve a better understanding of this process from your point of view we are undertaking a study asking people to tell us a bit more about themselves. We should like to do this some time in the next few weeks to see if there are any problems or difficulties arising for you as a result of this illness and its treatment for yourself and your family.

If you are willing to take part in this project it will involve giving some background information about yourself and your situation and then completing some brief questionnaires for us. These will be concerned with how you have been feeling in the past month, the impact the illness has on certain aspects of your life (social life and family relationships) and finally the type of support that you have found useful from family and friends.

These questionnaires help us to understand some aspects of the illness's impact on you but we should also like to interview you directly. These interviews will take place at your convenience and will aim to ask you about your experiences to date.

You are under no obligation to take part in this study and you can of course withdraw at any time.

PN90

The information you give will be treated in strictest confidence and will not affect treatment in any way. If the interviewer feels that you are expressing worries which may be helped by medical care, the interviewer may wish to discuss this with your own doctor. This would only be done however after consultation with you. The information given will be analysed anonymously along with that from other people who have agreed to help us in our study. We hope that information gained from this study may help us improve the care we provide to patients and their families.

Thank you for your co-operation.

Nigel North
(Researcher)

LOTHIAN HEALTH BOARD
DEPARTMENT OF CLINICAL ONCOLOGY
WESTERN GENERAL HOSPITAL AND ROYAL INFIRMARY, EDINBURGH

ICRF MEDICAL ONCOLOGY UNIT
Professor J. F. SMYTH
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Please direct all correspondence to:
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WESTERN GENERAL HOSPITAL
EDINBURGH EH4 2XU
Telephone: 031 332 2525 Ext. ____

CONSENT FORM

I, _____,

have had the attached study explained to me by _____

and I agree to take part. I understand that I can withdraw from the

project at any time.

Signed _____

Date _____

Appendix 2

I N T E R V I E W S C H E D U L E "P A T I E N T"

Physical illness not only causes symptoms but often affects other aspects of people's lives e.g. their families or their work. For this reason we are asking patients to tell us a bit more than usual about themselves to help us put research on the effects of illness and treatment into the context of people's lives as a whole.

I Biographical Data

1. Age: .....

2. Sex M = 1 F = 2

3. Marital Status:

M/Cohab	Sep/Div	Wid	S
1	2	3	4

4. How would you describe your relationship generally?

Good	Fair	Poor	V. Poor	N/A
1	2	3	4	9

5. Are religious beliefs an important part of your life? No = 0 Yes = 1

II Occupation

I would now like to ask you some questions about your work.

1. Occupation: .....

Do you work at the moment: No = 0 Yes = 1

F/T	P/T	U	R	H/W	Other
1	2	3	4	5	6

.....

Did you need any special training for that?

No qualifications	0
School certificates	1
Some further training	2
Full college/univ/prof. training	3

III Health and Illness

1. Until this illness, how has your own health been over the years?

Good	Fair	Poor
0	1	2

2. Have you been admitted to hospital for treatment before?

No	Childbearing only	Yes
0	1	2

3a. Has anyone close to you been treated for cancer? No = 0 Yes = 1

b. If Yes, how long ago was that?

Within past year	0
Within 5 years	1
More than 5 years	2
N/A	9

c. Did that involve hospital treatment? No = 0 Yes = 1 N/A = 9

d. If Yes, was that in this hospital? No = 0 Yes = 1

e. How satisfactory was that? N/A = 9

Very Positive	Satisfactory	Unsatisfactory	Very Negative
0	1	2	3

4. Have you ever needed treatment in the past for any 'nervous trouble', e.g. anxiety, depression? If Yes, clarify:

None	G.P.	Psychiatric O.P.	Psychiatric I.P.
0	1	2	3

How long ago was that?

Episode in last year	0
Episode in past 5 years	1
Episode more than 5 years ago	2
Chronic history (1 year duration)	3
N/A	9

IV The Illness and its Treatment - Attitudes and Evaluation

People differ in their attitude to illness and treatment.

1a Do you feel it is better for you to try to accept this illness or try to fight it?

Accept = 0 Fight = 1 D.K. = 9

b In general, do you feel hopeful or pessimistic about the outlook at present?

Pessimistic = 0 Hopeful = 1 D.K. = 9

c Do you prefer to leave decisions about your treatment to the doctors or do you prefer to have a say in those decisions?

Passive = 0 Active = 1 D.K. = 9

2. What is your main worry in relation to your illness at this stage? .....

.....

.....

.....

3. What is your main worry about treatment just now? .....

.....

.....

4. What do you require most from treatment at this stage?

a) That it should relieve troublesome symptoms as soon as possible
b) That it should concentrate on longer term control of the disease, even if it means feeling unwell for a time now
c) That short-term relief and longer term control are equally important
d) Other (specify): .....

.....

5. Have you felt any benefit from treatment so far? No = 0 Yes = 1

If Yes, what was that? .....

.....

.....

6. What is the aim of treatment at the moment? .....

.....

7. People differ in the amount of time they give to thinking about an illness. Do you:

- Find it is on your mind all the time? 3
- Find it is sometimes on your mind and sometimes not? 2
- Try not to think about it? 1
- Find you don't think about it? 0

8. People also differ in their attitude to talking about illness. Do you:

- Talk to anyone about it quite openly? 3
- Talk to selected people at selected times? 2
- Not volunteer anything but reply if asked? 1
- Prefer to avoid the subject? 0

9. Who has helped you most to cope with difficulties that have arisen for you in coping with this illness and its treatment?

- Doctors	Spouse	Other:.....
- Nurses	Relatives	
- Other Patients	Friends	

10. Apart from the medical care itself, is there more that the hospital services could do to help patients with illnesses like yours? .....

.....

.....

.....

V. Social Support

1. Do you feel that you know people who can give you help and support if you need it?

No	Friends	Relatives	Friends & Relatives	Other (specify) ...
0	1	2	3	4 .....

2. Who or what do you now see as your main social support?

Spouse	Family	Friends	Church	Other (specify) .....
1	2	3	4	5 .....

VI. Staff Support

1. Do you feel you have had adequate contact with the doctors? No = 0 Yes = 1

In what way could it be improved? .....

.....

2. Do you feel you have had adequate contact with the nurses? No = 0 Yes = 1

In what way could it be improved? .....

.....

VII. Personal and Social Relationships

The following questions are all concerned with your feelings since you first learnt what your illness was.

1. Since you first found out what was wrong with you, have you noticed any changes in your relationship with your husband/wife/friend? No = 0 Yes = 1

If Yes, in what way?

Closer	More Distant	Other (specify): .....
1	2	3 .....

2. Have you noticed any difference in the amount of communication between the two of you? No = 0 Yes = 1

If Yes, in what way?

More	Less	Other (specify): .....
1	2	3 .....

3. Has there been any change in the amount of social interaction outside the home?

	No Change	Increase	Decrease
a) With friends?	0	1	2
b) With relatives?	0	1	2

4a. Has there been any change in the support you have received from people since you first became ill?

No change	Increase	Decrease
0	1	2

b. In the past month do you feel that there has been any change in the support you have received from friends and family?

	No Change	Increase	Decrease
Family	0	1	2
Friends	0	1	2

c. In the past month do you feel that there has been any change in the availability of family and friends in whom you can confide or share your worries?

	No Change	Increase	Decrease
Family	0	1	2
Friends	0	1	2

5. How do you feel the illness and its treatment has affected the family as a whole?

.....

.....

.....

6. Has the amount of time that you have given to your leisure interests and activities changed during this time?

No change	Decrease	Increase	Other (specify):....
0	1	2	3 .....

7. In the past, have you had a particular person with whom you have shared your worries and problems, either inside or outside the family? No = 0 Yes = 1

If Yes, specify: .....

PATIENT DETAILS - NOTES

Diagnosis	NSCLC - 1
	SCCB - 2
Treatment Status	Active Treatment - 1
	Follow-up - 2
	Palliative Treatment - 3
Performance Status	0 1 2 3 4
Current Treatment	None
	Active Chemo Treatment
	Palliative Chemo Treatment
	Palliative XRT
Extent of Disease	Limited
	Extensive
	Progressive

Time Since Diagnosis ..... months

I N T E R V I E W S C H E D U L E "P R I M A R Y C A R E R"

Physical illness not only causes distress in patients but often affects other aspects of their lives e.g. their families. For this reason we are asking relatives to tell us about themselves to help us put research on the effects of illness and treatment into a wider context.

I Biographical Data

1. Relationship to patient?
1 - Spouse 2 - Relative (specify:.....) 3 - Friend

2. Age: .....

3. Sex M - 1 F - 2

4. Marital Status:

M/Cohab	Sep/Div	Wid	S
1	2	3	4

5. How would you describe your relationship generally?

Good	Fair	Poor	V. Poor	N/A
1	2	3	4	9

6. Are religious beliefs an important part of your life? No - 0 Yes - 1

II Occupation

I would now like to ask you some questions about your work.

1. Occuption: .....

Do you work at the moment? No - 0 Yes - 1

F/T	P/T	U	R	H/W	Other (specify): .....
1	2	3	4	5	6 .....

2. Have you been working in the past year? No - 0 Yes - 1

If Yes, specify: .....
F/T - 1 P/T - 0

3. Reason for giving up job: .....

.....

.....

III Health and Illness

1. In general, do you enjoy good health? No - 0 Yes - 1

2. How has your health been since your husband/wife/friend became ill?

Good	Fair	Poor
0	1	2

3a. Has anyone else close to you ever been treated for cancer? No = 0 Yes = 1

If Yes, specify: .....

b. How long ago was that?

Within past year	0
Within past 5 years	1
More than 5 years	2
N/A	9

c. Did that involve hospital treatment? No = 0 Yes = 1 N/A = 9

d. If yes, was that in this hospital? No = 0 Yes = 1

e. How satisfactory was that?

Very Positive	Satisfactory	Unsatisfactory	Very Negative
0	1	2	3

4. Have you ever needed treatment in the past for any 'nervous trouble', e.g. anxiety, depression?

None	G.P.	Psychiatric O.P.	Psychiatric I.P.
0	1	2	3

How long ago was that?

Episode in last year	0
Episode in past 5 years	1
Episode more than 5 years ago	2
Chronic history (1 year duration)	3
N/A	9

IV The Illness and its Treatment - Attitudes and Evaluation

People differ in their attitude to illness and treatment.

1a Do you feel it is better for your husband/wife/friend to try to accept this illness or try to fight it?

Accept = 0 Fight = 1 D.K. = 9

b In general, do you feel hopeful or pessimistic about the outlook at present?

Pessimistic = 0 Hopeful = 1 D.K. = 9

c Do you prefer to leave decisions about your husband's/wife's/friend's treatment to the doctors or do you prefer to have a say in those decisions?

Passive = 0 Active = 1 D.K. = 9

2. What is your main worry in relation to your husband's/wife's/friend's illness this stage? .....

.....

.....

3. What is your main worry about your husband's/wife's/friend's treatment just now?

.....

.....

.....

4. What are your hopes and expectations of the treatment at this stage?

a) That it should relieve troublesome symptoms as soon as possible
b) That it should concentrate on longer term control of the disease, even if it means feeling unwell for a time
c) That short-term relief and longer term control are equally important
d) Other (specify):
.....

5. Do you feel your husband/wife/friend has benefitted from treatment so far?
No = 0 Yes = 1

If Yes, what was that? .....

.....

.....

6. What is the aim of your husband's/wife's/friend's treatment at the moment?

.....

7. People differ in the amount of time they give to thinking about an illness. Do you:

- Find it is on your mind all the time? 3
- Find it is sometimes on your mind and sometimes not? 2
- Try not to think about it? 1
- Find you don't think about it? 0

8. People also differ in their attitude to talking about illness. Do you:

- Talk to anyone about it quite openly? 3
- Talk to selected people at selected times? 2
- Not volunteer anything but reply if asked? 1
- Prefer to avoid the subject? 0

9. Who has helped you most to cope with difficulties that have arisen for you in coping with your husband's/wife's/friend's illness and its treatment?

- Doctors
- Nurses
- Other Patients
- Spouse
- Relatives
- Friends
- Other: .....

10. Apart from the medical care itself, is there more that the hospital services could do to help families cope with this sort of illness? .....

.....

.....

.....

V. Social Support

1. Do you feel that you know people who can give you help and support if you need it?

No	Friends	Relatives	Friends & Relatives	Other (specify) .....
0	1	2	3	4 .....

2. Who or what do you now see as your main social support?

Spouse	Family	Friends	Church	Other (specify) .....
1	2	3	4	5 .....

VI. Staff Support

1. Do you feel you have had adequate contact with the doctors? No = 0 Yes = 1

In what way could it be improved? .....

.....

2. Do you feel you have had adequate contact with the nurses? No = 0 Yes = 1

In what way could it be improved? .....

.....

VII. Personal and Social Relationships

The following questions are all concerned with your feelings since you first learned what your husband/wife/friend's illness was.

1. Since you first found out what was wrong with your husband/wife/friend, have you noticed any changes in your relationship? No = 0 Yes = 1

If Yes, in what way?

Closer	More Distant	Other (specify): .....
1	2	3 .....

2. Have you noticed any difference in the amount of communication beetween the two of you?

No = 0 Yes = 1

If Yes, in what way?

More	Less	Other (specify): .....
1	2	3 .....

3. Has there been any change in the amount of social interaction outside the home?

	No Change	Increase	Decrease
a) With friends?	0	1	2
b) With relatives?	0	1	2

4a. Has there been any change in the support you have received from people generally during this time?

	No Change	Increase	Decrease
	0	1	2

b. In the past month do you feel that there has been any change in the support you have received from friends and family?

	No Change	Increase	Decrease
Family	0	1	2
Friends	0	1	2

c. In the past month do you feel that there has been any change in the availability of family and friends in whom you can confide or share your worries?

	No Change	Increase	Decrease
Family	0	1	2
Friends	0	1	2

5. How do you feel the illness and its treatment has affected the family as a whole so far?

.....

.....

.....

6. At this stage, how do you see your own role in the treatment of your husband's/wife's/friend's disease?

None	Support	Help come to terms with disease	Help fight disease	Other (specify): ....
0	1	2	3	4

7. Has the amount of time that you have given to your own leisure interests and activities changed during this time?

No change	Decrease	Increase	Other (specify): ....
0	1	2	3

8. In the past, have you had a particular person with whom you have shared your worries and problems - either inside or outside the family? No - 0 Yes - 1

If Yes, specify: .....

PERCEIVED SOCIAL SUPPORT SCALE

Directions: The statements which follow refer to feelings and experiences which occur to most people at one time or another in their relationships with friends. For each statement there are three possible answers: Yes, No, Don't know. Please circle the answer you choose for each item.

Yes	No	Don't know	1. My friends give me the moral support I need.
Yes	No	Don't know	2. Most other people are closer to their friends than I am.
Yes	No	Don't know	3. My friends enjoy hearing about what I think.
Yes	No	Don't know	4. Certain friends come to me when they have problems or need advice.
Yes	No	Don't know	5. I rely on my friends for emotional support.
Yes	No	Don't know	6. If I felt that one or more of my friends were upset with me, I'd just keep it to myself.
Yes	No	Don't know	7. I feel that I'm on the fringe in my circle of friends.
Yes	No	Don't know	8. There is a friend I could go to if I were just feeling down, without feeling funny about it later.
Yes	No	Don't know	9. My friends and I are very open about what we think about things.
Yes	No	Don't know	10. My friends are sensitive to my personal needs.
Yes	No	Don't know	11. My friends come to me for emotional support.
Yes	No	Don't know	12. My friends are good at helping me solve problems.
Yes	No	Don't know	13. I have a deep sharing relationship with a number of friends.
Yes	No	Don't know	14. My friends get good ideas about how to do things or make things from me.
Yes	No	Don't know	15. When I confide in friends, it makes me feel uncomfortable.
Yes	No	Don't know	16. My friends seek me out for companionship.
Yes	No	Don't know	17. I think that my friends feel that I'm good at helping them solve problems.
Yes	No	Don't know	18. I don't have a relationship with a friend that is as intimate as other people's relationships with friends.
Yes	No	Don't know	19. I've recently had a good idea about how to do something from a friend.
Yes	No	Don't know	20. I wish my friends were much different.

Perceived Social Support Scale

Directions: The statements which follow refer to feelings and experiences which occur to most people at one time or another in their relationships with their families. For each statement there are three possible answers: Yes, No, Don't know. Please circle the answer you choose for each item.

Yes	No	Don't know	1. My family gives me the moral support I need.
Yes	No	Don't know	2. I get good ideas about how to do things or make things from my family.
Yes	No	Don't know	3. Most other people are closer to their family than I am.
Yes	No	Don't know	4. When I confide in the members of my family who are closest to me, I get the idea that it makes them uncomfortable.
Yes	No	Don't know	5. My family enjoys hearing about what I think.
Yes	No	Don't know	6. Members of my family share many of my interests.
Yes	No	Don't know	7. Certain members of my family come to me when they have problems or need advice.
Yes	No	Don't know	8. I rely on my family for emotional support.
Yes	No	Don't know	9. There is a member of my family I could go to if I were just feeling down, without feeling funny about it later.
Yes	No	Don't know	10. My family and I are very open about what we think about things.
Yes	No	Don't know	11. My family is sensitive to my personal needs.
Yes	No	Don't know	12. Members of my family come to me for emotional support.
Yes	No	Don't know	13. Members of my family are good at helping me solve problems.
Yes	No	Don't know	14. I have a deep sharing relationship with a number of members of my family.
Yes	No	Don't know	15. Members of my family get good ideas about how to do things or make things from me.
Yes	No	Don't know	16. When I confide in members of my family, it makes me uncomfortable.
Yes	No	Don't know	17. Members of my family seek me out for companionship.
Yes	No	Don't know	18. I think that my family feels that I'm good at helping them solve problems.
Yes	No	Don't know	19. I don't have a relationship with a member of my family that is as close as other people's relationships with family members.
Yes	No	Don't know	20. I wish my family were much different.

Symptoms and Side Effects Scale

Date.....

Please answer each of these questions about your health by circling the number which best applies to you.

In the past week, how have you been troubled by the following?:

	Not at all	A Little	Quite a bit	Very Much
1.Shortness of breath	1	2	3	4
2. Pain	1	2	3	4
3. Difficulty sleeping	1	2	3	4
4. Tiredness	1	2	3	4
5. Nausea	1	2	3	4
6. Poor appetite	1	2	3	4
7. Hair loss	1	2	3	4
8. Feeling generally unwell	1	2	3	4

Have you been feeling troubled by any others symptoms or side-effects from your treatment this week? If so, please mention these here and circle the appropriate number as before to show how much of a problem this has been to you this week.

a)_____	1	2	3	4
b)_____	1	2	3	4
c)_____	1	2	3	4

ECOG Performance Status Scale

0. Fully active, able to carry out all pre-disease activities without restriction and without the aid of analgesia.

1. Restricted in strenuous activity but ambulatory and able to carry out light work or pursue a sedentary occupation. Patients who are fully active but require analgesia.

2. Ambulatory and capable of all self care but unable to carry out any work. Up and about more than 50 per cent of waking hours.

3. Capable of only limited self care, confined to bed or chair more than 50 per cent of waking hours.

4. Completely disabled. Unable to carry out any self care and confined totally to bed or chair.

Appendix 3

CORRELATION MATRIX (FIRST LINE MANAGEMENT)

	page1	sage1	panx1	sanx1	pdep1	sdep1	ppssfa1	spssfa1
age1	1							
age1	.742	1						
anx1	-.104	-.097	1					
anx1	-.145	-.145	.45	1				
dep1	-.072	-.007	.709	.414	1			
dep1	-.048	-.099	-.011	.644	.188	1		
pssfa1	.109	.035	.248	.306	.297	.201	1	
pssfa1	-.019	-.09	.393	.471	.333	.317	.704	1
pssfr1	.007	.036	.078	-.109	.023	-.116	.558	.405
pssfr1	.054	-.067	.284	.177	.246	.205	.253	.543
se1	-.021	-.153	.005	-.258	-.176	.064	.351	.278
ev1	.066	-.029	-.061	-.318	-.205	.024	.281	.185
ghq1	-.311	-.436	.476	.671	.487	.421	.35	.372
ghq2	-.111	-.168	.339	.869	.32	.678	.328	.439
ghq3	-.193	-.335	.448	.594	.486	.547	.348	.42
ghq4	-.104	-.082	.258	.574	.293	.279	.203	.089

	page1	sage1	panx1	sanx1	pdep1	sdep1	ppssfa1	spssfa1
ghqt	-.221	-.325	.469	.831	.485	.614	.383	.435
p1p	.114	.25	.115	-.021	.034	.08	-.095	-.002
p2p	-.038	-.169	.09	.075	.021	.026	.011	.053
p3p	.124	.157	-.082	.057	-.226	-.091	-.372	-.182
p4p	-.057	.026	.096	-.197	.195	-.334	-.107	-.065
p5p	.032	.012	-.011	-.169	-.192	-.223	-.064	-.117
p6p	.256	.254	.036	.168	.048	.04	.16	.016
p7p	.305	.281	.293	.168	.316	.003	-.086	-.076
ptp	.216	.225	.177	.059	.079	-.17	-.164	-.107
p1s	.198	.3	-.098	-.311	.067	-.144	-.358	-.248
p2s	.007	-.022	-.05	-.037	-.168	.022	.158	.029
p3s	.238	.300	-.031	-.161	-.004	-.066	-.099	-.128
p4s	-.1	-.148	-.009	.206	.075	.185	-.048	-.043
p5s	-.077	-.075	.033	.067	-.207	.13	-.122	-.036
p6s	-.192	-.217	.081	.151	.182	.222	.148	.119
p7s	.296	.301	.175	.188	.272	.083	.159	.038

CORRELATION MATRIX (FIRST LINE MANAGEMENT)

	page1	sage1	panx1	sanx1	pdep1	sdep1	ppssfa1	spssfa1
1pts	.094	.171	.061	.121	.086	.256	-.015	-.077
1epep	-.081	-.184	.03	-.097	-.033	-.108	-.008	-.013
1epnp	.177	.211	.044	.15	.204	.295	.197	.034
1epes	-.142	-.32	-.023	.226	-.159	.108	.014	.195
1epns	.365	.436	-.125	-.086	-.203	-.074	.127	-.052
ps1	-.067	-.065	-.136	.323	-.071	.208	-.055	-.01
1time	.102	.124	-.172	.037	-.067	.031	-.036	-.021

	ppssfr1	spssfr1	sse1	sev1	1ghq1	1ghq2	1ghq3	1ghq4
ppssfr1	1							
spssfr1	.249	1						
sse1	.437	.299	1					
sev1	.384	.182	.903	1				
1ghq1	.096	.165	-.103	-.213	1			
1ghq2	-.072	.104	-.115	-.159	.729	1		
1ghq3	.089	.163	.072	.051	.725	.669	1	
1ghq4	.018	-.001	-.229	-.258	.518	.406	.227	1

CORRELATION MATRIX (FIRST LINE MANAGEMENT)

	ppssfr1	spssfr1	sse1	sev1	1ghq1	1ghq2	1ghq3	1ghq4
ghqt	.037	.144	-.091	-.154	.915	.893	.849	.566
p1p	-.147	.201	.007	-.051	-.162	-.104	-.178	-.17
p2p	-.129	.108	.188	.067	.192	.149	.111	-.007
p3p	-.273	-.233	-.278	-.256	-.075	.047	-.126	-.062
p4p	-.111	-.096	-.14	-.06	-.019	-.111	-.056	-.115
p5p	.216	-.146	.137	.144	-.218	-.166	-.067	-.118
p6p	-.014	-.106	-.159	-.134	.037	.16	.056	.207
p7p	-.091	-.149	-.334	-.25	-.049	.123	.159	.023
ptp	-.212	-.152	-.176	-.176	-.005	.1	.025	-.039
p1s	-.194	-.028	.024	.001	-.264	-.268	-.189	-.161
p2s	.068	-.216	.333	.316	-.03	.114	.307	-.135
p3s	.028	.109	-.146	-.077	-.259	-.15	-.185	-.259
p4s	-.109	-.139	.012	-.046	.186	.088	-.049	.248
p5s	.028	.026	.151	.142	.158	.174	.088	-.152
p6s	.193	.3	.162	.089	.046	.056	.151	.127
p7s	-.024	.13	-.207	-.092	.195	.108	.224	.121

	ppssfr1	spssfr1	sse1	sev1	1ghq1	1ghq2	1ghq3	1ghq4
pts	.035	.087	.192	.178	.077	.118	.207	-.049
epep	.083	-.05	.185	.24	.206	.01	.1	.02
epnp	.046	.234	.126	.126	.1	.176	.264	.068
epes	.116	.001	-.039	-.143	.347	.128	.11	.292
epns	-.056	-.217	-.044	.041	-.189	.069	-.187	-.186
s1	.048	.046	-.337	-.412	.142	.235	.008	.217
time	-.118	-.062	-.308	-.263	-.058	.053	-.108	.239

CORRELATION MATRIX (FIRST LINE MANAGEMENT)

	1ghqt	1p1p	1p2p	1p3p	1p4p	1p5p	1p6p	1p7p
1ghqt	1							
1p1p	-.179	1						
1p2p	.151	.02	1					
1p3p	-.059	.16	.314	1				
1p4p	-.086	-.016	.112	.07	1			
1p5p	-.173	-.015	.11	.183	-.077	1		
1p6p	.126	-.229	-.327	-.221	-.224	-.118	1	
1p7p	.088	.044	-.055	.176	.352	.093	.134	1
1ptp	.037	.132	.603	.598	.47	.325	.004	.557
1p1s	-.273	.106	-.107	.108	-.066	.091	-.053	-.198
1p2s	.112	-.32	.146	-.113	-.12	.07	.219	.119
1p3s	-.244	.126	-.186	.091	-.283	-.035	.086	-.02
1p4s	.118	.06	.391	.209	.127	-.028	-.198	.173
1p5s	.116	.039	-.157	.078	-.487	-.213	.14	-.32
1p6s	.108	.025	.065	-.266	-.076	.186	-.019	-.001
1p7s	.197	.232	-.204	-.122	.083	-.218	.448	.133

	1ghqt	1p1p	1p2p	1p3p	1p4p	1p5p	1p6p	1p7p
1pts	.128	.091	.039	-.028	-.38	-.062	.269	-.023
1epep	.105	-.166	.495	.046	.189	.19	-.355	-.186
1epnp	.197	.128	-.276	-.385	-.314	-.378	.306	-.041
1epes	.244	-.22	.249	.035	-.251	.108	-.161	-.192
1epns	-.129	.349	.266	.386	.201	.301	-.075	.123
ps1	.172	.056	-.181	.12	-.216	.025	.302	.109
1time	.008	-.142	-.072	.042	.203	-.103	.142	.154

CORRELATION MATRIX (FIRST LINE MANAGEMENT)

	1ptp	1p1s	1p2s	1p3s	1p4s	1p5s	1p6s	1p7s
ptp	1							
p1s	-.09	1						
p2s	.085	-.113	1					
p3s	-.143	.216	-.038	1				
p4s	.323	-.242	-.162	-.364	1			
p5s	-.338	.072	.095	.31	-.384	1		
p6s	-.045	-.322	.055	.001	.175	-.35	1	
p7s	.062	-.051	-.192	.202	-.093	.044	.036	1

	1ptp	1p1s	1p2s	1p3s	1p4s	1p5s	1p6s	1p7s
pts	-.041	.058	.35	.519	.089	.321	.406	.386
epep	.196	-.034	.104	-.282	.081	.015	-.158	-.168
epnp	-.382	.198	.087	.241	-.343	.331	-.172	.448
epes	-.068	-.108	-.062	-.343	.313	-.029	-.083	-.268
epns	.496	-.052	-.055	.11	-.01	-.123	-.173	.126
s1	.02	-.242	-.146	.094	.148	.059	.243	.049
time	.106	.082	-.042	.017	-.127	-.265	-.181	-.114

CORRELATION MATRIX (FIRST LINE MANAGEMENT)

	1pts	1epep	1epnp	1epes	1epns	ps1	1time
1pts	1						
1epep	-.185	1					
1epnp	.282	-.312	1				
1epes	-.215	.413	-.254	1			
1epns	-.104	.101	-.181	-.333	1		
ps1	.153	-.574	.002	-.04	-.013	1	
1time	-.333	-.066	-.073	.033	.104	.036	1

CORRELATION MATRIX (FOLLOW UP SURVEILLANCE)

	page2	sage2	panx2	sanx2	pdep2	sdep2	ppssfa2	spssfa2
age2	1							
age2	.809	1						
anx2	-.222	-.201	1					
anx2	-.123	-.209	.375	1				
dep2	-.135	-.052	.785	.224	1			
dep2	-.244	-.317	-.007	.575	-.075	1		
pssfa2	-.227	-.167	.029	.112	.134	.294	1	
ssfa2	-.105	-.11	.011	.143	.111	.337	.937	1
pssfr2	-.158	-.337	-.092	.358	-.011	.472	.341	.442
pssfr2	-.191	-.326	.026	.212	.022	.329	.282	.39
se2	.151	-.037	-.053	.04	-.134	.025	-.26	-.219
ev2	.136	-.027	-.154	.097	-.25	.105	-.245	-.245
ghq1	-.168	-.242	.177	.478	.071	.339	.03	.026
ghq2	-.296	-.453	.399	.567	.106	.425	-.019	.007
ghq3	-.007	-.031	.076	.38	-.02	.265	.011	-.011
ghq4	-.163	-.138	.124	.448	.038	.41	.061	.046

	page2	sage2	panx2	sanx2	pdep2	sdep2	ppssfa2	spssfa2
ghqt	-.234	-.321	.284	.635	.075	.49	.025	.024
p1p	-.021	-.038	.206	-.048	.377	-.079	-.133	-.095
p2p	-.122	-.121	.417	.157	.57	.011	-.132	-.107
p3p	.037	-.001	.373	.12	.394	.079	-.071	-.074
p4p	.03	-.023	.185	.076	.245	.056	.013	-.052
p5p	-.167	-.051	.308	-.001	.455	.003	.157	.106
p6p	-.153	-.121	.31	-.209	.397	-.131	-.037	-.064
p7p	-.138	-.02	.359	-.131	.484	-.237	-.035	-.048
ptp	-.09	-.058	.363	-.007	.488	-.051	-.023	-.048
p1s	-.079	-.067	-.001	.347	.148	.282	.165	.157
p2s	-.281	-.167	.154	.438	.112	.229	.023	.001
p3s	.039	.077	.171	.317	.204	.102	.135	.109
p4s	-.067	-.087	.07	.437	.082	.375	.085	.102
p5s	-.053	-.099	.063	.305	.027	.08	.162	.179
p6s	-.118	-.135	-.118	.255	-.065	.343	.274	.221
p7s	-.086	-.067	-.013	.409	.069	.205	.059	.088

CORRELATION MATRIX (FOLLOW UP SURVEILLANCE)

	page2	sage2	panx2	sanx2	pdep2	sdep2	ppssfa2	spssfa2
2pts	-.096	-.085	.055	.436	.103	.281	.15	.147
2epep	.083	-.104	-.176	-.076	-.199	.079	-.001	.042
2epnp	.059	.061	.101	.13	.042	-.029	.004	.015
2epes	.111	.103	.234	-.161	.249	-.083	-.02	-.02
2epns	.279	.078	-.296	-.238	-.268	-.154	-.097	-.002
os2	.034	.149	.034	.253	-.034	-.065	-.208	-.209
2time	.095	.135	-.118	-.239	-.093	-.117	.174	.026

	ppssfr2	spssfr2	sse2	sev2	2ghq1	2ghq2	2ghq3	2ghq4
ppssfr2	1							
spssfr2	.618	1						
sse2	-.069	.049	1					
sev2	-.167	-.05	.896	1				
2ghq1	.047	-.063	-.099	.068	1			
2ghq2	.164	.18	.022	.088	.403	1		
2ghq3	-.069	.121	.124	.25	.617	.228	1	
2ghq4	.111	.053	-.069	-.019	.536	.265	.61	1

CORRELATION MATRIX (FOLLOW UP SURVEILLANCE)

	ppssfr2	spssfr2	sse2	sev2	2ghq1	2ghq2	2ghq3	2ghq4
2ghqt	.103	.101	-.016	.114	.828	.692	.747	.769
2p1p	.173	-.067	.145	.034	.007	-.092	-.185	-.1
2p2p	.085	-.08	.171	.111	.098	.089	-.051	-.004
2p3p	-.033	-.114	.261	.296	.356	.173	.207	.178
2p4p	-.096	-.147	.102	.3	.512	.172	.343	.198
2p5p	.02	-.223	-.092	-.025	.258	.087	-.047	-.029
2p6p	-.156	-.112	.023	.037	.132	.029	-.038	-.023
2p7p	-.104	-.155	.123	.073	.045	-.006	-.132	-.138
2ptp	-.038	-.164	.116	.153	.272	.089	.044	.025
2p1s	.26	.243	-.044	-.076	.495	.188	.47	.5
2p2s	.071	-.029	-.157	-.052	.651	.24	.556	.367
2p3s	.119	-.066	.091	-.034	.339	.041	.345	.282
2p4s	.258	.241	-.074	-.046	.574	.161	.678	.717
2p5s	.049	.123	-.066	-.049	.534	.159	.541	.342
2p6s	.237	.223	-.078	-.052	.454	.214	.442	.343
2p7s	.283	.199	-.257	-.284	.541	.146	.365	.47

	ppssfr2	spssfr2	sse2	sev2	2ghq1	2ghq2	2ghq3	2ghq4
2pts	.233	.173	-.102	-.111	.612	.189	.585	.543
2epep	.155	.092	.177	.169	.008	.008	.033	.081
2epnp	.094	.273	-.119	-.23	-.215	-.115	-.088	.116
2epes	.051	.096	.075	-.042	.065	-.19	.112	-.077
2epns	.019	.07	.041	.128	-.118	-.111	-.002	-.066
ps2	-.076	.056	-.125	-.161	.095	.142	.222	.095
2time	-.204	-.252	-.117	.086	.246	-.158	.217	.108

CORRELATION MATRIX (FOLLOW UP SURVEILLANCE)

	2ghqt	2p1p	2p2p	2p3p	2p4p	2p5p	2p6p	2p7p
2ghqt	1							
2p1p	-.114	1						
2p2p	.055	.754	1					
2p3p	.3	.632	.743	1				
2p4p	.391	.424	.493	.827	1			
2p5p	.101	.617	.686	.735	.709	1		
2p6p	.039	.653	.611	.754	.573	.613	1	
2p7p	-.066	.653	.638	.652	.508	.684	.664	1
2ptp	.146	.769	.811	.917	.813	.877	.818	.826
2p1s	.524	-.033	-.03	.084	.212	.072	-.085	-.084
2p2s	.574	-.108	.067	.058	.183	.027	-.069	.02
2p3s	.308	.003	-.028	.09	.072	-.008	-.146	.015
2p4s	.662	.053	.083	.265	.314	.068	-.026	-.007
2p5s	.489	-.193	-.202	-.067	.115	-.08	-.195	-.208
2p6s	.462	-.036	-.068	.084	.269	.127	-.108	-.037
2p7s	.486	-.08	-.094	-.06	.005	-.064	-.212	-.059

	2ghqt	2p1p	2p2p	2p3p	2p4p	2p5p	2p6p	2p7p
2pts	.605	-.058	-.045	.086	.197	.02	-.146	-.062
2epep	.041	-.097	-.182	-.069	.075	.047	-.26	-.001
2epnp	-.102	-.114	-.122	-.167	-.277	-.268	-.17	-.082
2epes	-.055	.124	.19	.184	.019	.058	.229	.224
2epns	-.107	-.108	-.341	-.101	.075	-.141	-.022	-.027
ps2	.177	-.155	-.053	-.097	-.109	-.14	-.198	0
2time	.105	0	-.007	.385	.581	.352	.223	.266

CORRELATION MATRIX (FOLLOW UP SURVEILLANCE)

	2ptp	2p1s	2p2s	2p3s	2p4s	2p5s	2p6s	2p7s
2ptp	1							
2p1s	.04	1						
2p2s	.049	.551	1					
2p3s	.008	.694	.584	1				
2p4s	.142	.696	.505	.554	1			
2p5s	-.12	.764	.689	.723	.588	1		
2p6s	.066	.74	.499	.607	.672	.671	1	
2p7s	-.086	.716	.597	.587	.695	.605	.636	1

	2ptp	2p1s	2p2s	2p3s	2p4s	2p5s	2p6s	2p7s
2pts	.018	.89	.731	.813	.838	.852	.823	.849
2epep	-.057	.219	-.024	.059	.036	.256	.208	.001
2epnp	-.216	-.212	-.292	-.143	.156	-.266	-.09	.109
2epes	.165	.193	.177	.166	.098	.072	-.062	.097
2epns	-.091	-.092	-.25	-.252	-.059	-.005	-.003	-.045
ps2	-.122	.011	.254	.117	.162	.114	.289	.226
2time	.357	.074	.023	.092	.336	.051	.263	.121

CORRELATION MATRIX (FOLLOW UP SURVEILLANCE)

	2pts	2epep	2epnp	2epes	2epns	ps2	2time
2pts	1						
2epep	.122	1					
2epnp	-.089	-.375	1				
2epes	.128	-.073	-.125	1			
2epns	-.113	.44	-.011	-.174	1		
ps2	.195	-.046	.272	-.314	.05	1	
2time	.179	.056	-.074	.052	.159	-.105	1

CORRELATION MATRIX (PALLIATIVE THERAPY GROUP)

	page3	sage3	panx3	sanx3	pdep3	sdep3	ppssfa3	spssfa3
page3	1							
sage3	.501	1						
panx3	-.168	-.148	1					
sanx3	-.171	.02	.273	1				
pdep3	.094	.013	.258	.098	1			
sdep3	-.219	-.006	.127	.667	.131	1		
ppssfa3	-.158	-.293	.285	.345	.202	.189	1	
spssfa3	-.11	-.404	.269	.306	.21	.169	.917	1
ppssfr3	-.316	-.263	-.127	.351	-.058	.337	.504	.48
spssfr3	-.16	-.417	.139	.063	.012	.207	.453	.498
3sse	.112	-.128	.364	.169	.2	.042	.161	.16
3sev	.267	-.014	.25	-.001	-.013	-.121	.025	.007
3ghq1	-.067	-.067	.34	.683	.19	.459	.158	.184
3ghq2	-.311	.060	.354	.79	.203	.519	.374	.295
3ghq3	.11	.006	.2	.521	.292	.304	-.002	.14
3ghq4	.374	.233	.184	.54	.144	.475	-.032	.035

	page3	sage3	panx3	sanx3	pdep3	sdep3	ppssfa3	spssfa3
3ghqt	-.007	.048	.368	.852	.265	.59	.195	.229
3p1p	.043	.055	.042	.209	-.165	.28	.027	-.003
3p2p	.001	-.147	.518	.136	.021	.138	.323	.326
3p3p	-.164	-.369	.263	.092	.034	.246	.154	.153
3p4p	.006	-.185	.256	.248	-.09	.467	.14	.183
3p5p	-.065	-.15	.246	.24	-.075	.183	.227	.144
3p6p	.073	-.277	.097	-.067	-.107	.02	.136	.114
3p7p	-.028	-.025	.371	.079	-.063	.189	-.046	.002
3ptp	-.026	-.216	.364	.187	-.079	.304	.197	.194
3p1s	.142	.113	-.047	.299	.369	.176	.184	.258
3p2s	.016	-.099	.188	.294	.219	.284	.104	.084
3p3s	-.17	-.077	-.168	-.05	-.465	.108	-.027	-.076
3p4s	.015	-.006	.036	-.003	-.068	-.056	.131	.045
3p5s	-.011	.262	-.201	.345	.08	.355	.012	-.127
3p6	-.271	-.223	.016	-.007	-.168	-.081	.026	.054
3p7s	.16	.149	.15	.568	.063	.258	.24	.226

CORRELATION MATRIX (PALLIATIVE THERAPY GROUP)

	page3	sage3	panx3	sanx3	pdep3	sdep3	ppssfa3	spssfa3
3pts	-.037	.045	.022	.428	.007	.281	.206	.152
3epep	.045	.019	-.02	.247	-.092	.02	-.133	.003
3epnp	.104	.276	.045	-.152	.085	-.012	.012	-.046
3epes	.074	.081	.094	-.165	.019	-.042	-.044	-.072
3epns	.099	.206	-.306	.253	.068	.156	-.078	-.108
ɔs3	.033	-.089	-.246	.158	-.163	.118	.133	.054
3time	-.097	.07	.104	-.02	.243	.163	.024	-.005

	ppssfr3	spssfr3	3sse	3sev	3ghq1	3ghq2	3ghq3	3ghq4
ɔpssfr3	1							
spssfr3	.539	1						
3sse	.104	.24	1					
3sev	-.027	.176	.84	1				
3ghq1	.18	.076	.265	.144	1			
3ghq2	.186	-.043	.115	.032	.652	1		
3ghq3	.032	.005	.11	.014	.385	.32	1	
3ghq4	-.131	.006	-.049	-.046	.396	.258	.623	1

CORRELATION MATRIX (PALLIATIVE THERAPY GROUP)

	ppssfr3	spssfr3	3sse	3sev	3ghq1	3ghq2	3ghq3	3ghq4
3ghqt	.107	.014	.154	.054	.834	.788	.703	.702
3p1p	-.057	-.003	.11	.186	.328	.261	-.025	.214
3p2p	-.104	.187	.36	.379	.171	.235	.007	.147
3p3p	.04	.037	.128	.142	.23	.195	-.075	.003
3p4p	.075	.178	.228	.163	.312	.227	-.008	.289
3p5p	.009	.065	.288	.366	.206	.359	-.106	.056
3p6p	-.09	.236	.132	.177	-.186	-.049	-.048	.125
3p7p	-.187	.1	.322	.299	.216	.07	.046	.25
3ptp	-.056	.161	.31	.331	.255	.255	-.037	.214
3p1s	.245	-.004	.051	-.122	.226	.2	.131	.261
3p2s	-.049	-.1	.226	.161	.152	.312	.28	.328
3p3s	.278	.026	-.033	-.043	-.129	-.14	-.054	-.082
3p4s	.01	-.105	-.024	.094	-.08	-.009	.096	.093
3p5s	.153	-.228	.038	-.048	.071	.262	.164	.156
3p6	.049	-.166	-.102	-.005	-.202	-.013	.069	-.027
3p7s	.016	-.153	.037	.136	.546	.564	.291	.447

	ppssfr3	spssfr3	3sse	3sev	3ghq1	3ghq2	3ghq3	3ghq4
3pts	.176	-.223	.047	.067	.186	.362	.295	.353
3epep	.024	-.121	.116	-.024	.113	.043	.317	.041
3epnp	-.024	-.016	-.14	-.119	-.065	-.033	-.175	-.059
3epes	.031	.21	.018	.151	-.082	-.061	-.103	-.017
3epns	-.001	-.141	.026	.007	-.002	.132	.174	.109
ps3	.005	.125	.089	.141	.159	.123	-.102	.041
3time	.099	.295	.091	-.042	-.078	.002	.153	.031

CORRELATION MATRIX (PALLIATIVE THERAPY GROUP)

	3qhqt	3p1p	3p2p	3p3p	3p4p	3p5p	3p6p	3p7p
3ghqt	1							
3p1p	.28	1						
3p2p	.201	.31	1					
3p3p	.143	.461	.489	1				
3p4p	.288	.437	.591	.56	1			
3p5p	.207	.648	.483	.657	.437	1		
3p6p	-.061	.311	.378	.471	.393	.438	1	
3p7p	.193	.543	.69	.279	.64	.309	.296	1
3ptp	.249	.69	.79	.756	.809	.749	.619	.738
3p1s	.272	-.068	-.068	.002	.042	-.15	.032	-.038
3p2s	.347	.098	.299	.122	.287	.053	.182	.212
3p3s	-.14	.083	.07	.098	.117	.033	-.022	.052
3p4s	.02	.052	-.091	.078	-.176	.168	.114	-.166
3p5s	.217	-.029	-.232	-.027	-.024	-.038	-.013	-.144
3p6	-.069	-.247	.154	.076	-.037	-.122	.189	-.01
3p7s	.627	.387	.266	.22	.183	.309	.12	.225

	3qhqt	3p1p	3p2p	3p3p	3p4p	3p5p	3p6p	3p7p
3pts	.39	.088	.147	.179	.11	.093	.194	.053
3epep	.149	-.12	-.106	-.224	-.042	-.002	-.232	-.017
3epnp	-.098	.234	-.06	.043	.089	-.161	.073	.192
3epes	-.084	-.091	.008	-.063	-.127	-.205	.159	-.009
3epns	.128	.003	-.239	-.142	-.184	-.074	-.077	-.255
ps3	.093	.117	.199	.03	.1	.109	-.043	.013
3time	.02	.024	.029	-.199	.085	-.022	-.043	.149

CORRELATION MATRIX (PALLIATIVE THERAPY GROUP)

	3ptp	3p1s	3p2s	3p3s	3p4s	3p5s	3p6	3p7s
3ptp	1							
3p1s	-.044	1						
3p2s	.256	.158	1					
3p3s	.088	-.24	-.037	1				
3p4s	-.021	-.024	.15	-.113	1			
3p5s	-.105	.415	.069	.099	.106	1		
3p6	.011	-.052	.397	.23	.045	-.035	1	
3p7s	.326	.364	.348	-.229	.191	.195	.176	1

	3ptp	3p1s	3p2s	3p3s	3p4s	3p5s	3p6	3p7s
3pts	.168	.445	.632	.151	.417	.48	.571	.659
3epep	-.141	.028	-.183	.24	-.235	.185	-.103	-.058
3epnp	.073	-.046	-.126	.043	-.094	-.017	-.172	.023
3epes	-.064	.135	-.111	-.101	-.115	.2	.061	.111
3epns	-.197	.151	.044	-.251	.202	.268	-.027	.106
ps3	.11	-.139	.143	-.011	-.098	.084	-.142	-.034
3time	.008	-.005	.01	-.123	-.155	.046	-.199	-.287

CORRELATION MATRIX (PALLIATIVE THERAPY GROUP)

	3pts	3epep	3epnp	3epes	3epns	ps3	3time
3pts	1						
3epep	-.07	1					
3epnp	-.121	-.27	1				
3epes	.056	-.164	.234	1			
3epns	.146	-.026	.024	-.041	1		
ps3	-.07	-.184	-.271	-.247	.204	1	
3time	-.235	.089	-.176	.19	.045	-.114	1

KEY TO CORRELATION MATRICES

Page	Age of patient
Sage	Age of carer
Panx	Patient anxiety
Sanx	Carer anxiety
Pdep	Patient depression
Sdep	Carer depression
Ppssfa	Patient perceived support from family
Spssfa	Carer perceived support from family
Ppssfr	Patient perceived support from friends
Spssfr	Carer perceived support from friends
Sse	Number of symptoms and side effects
Sev	Severity of symptoms and side effects
ghq1	GHQ: somatic symptoms
ghq2	GHQ: anxiety and insomnia
ghq3	GHQ: social dysfunction
ghq4	GHQ: severe depression
ghqt	GHQ: total
P1p	PAIS (health care orientation): patient
P2p	PAIS (vocational environment): patient
P3p	PAIS (domestic environment): patient
P4p	PAIS (sexual relationship): patient
P5p	PAIS (extended family): patient
P6p	PAIS (social relationships): patient
P7p	PAIS (psychological distress): patient
Ptp	(PAIS (total): patient
P1s	PAIS (health care orientation): carer
P2s	PAIS (vocational environment): carer
P3s	PAIS (domestic environment): carer
P4s	PAIS(sexual relationship): carer
P5s	PAIS(extended family): carer
P6s	PAIS(social relationships): carer
P7s	PAIS(psychological distress): carer
Pts	PAIS(total):carer
epep	EPI(extraversion): patient
epnp	EPI(neuroticism):patient
epes	EPI(extraversion): carer
epns	EPI(neuroticism): carer
ps	performance status
time	time since diagnosis